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Home care for patients in need of advanced care and technology -a challenge for patients and their caregivers

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Stockholm 2014

Published by Karolinska Institutet.
Printed by Universitetsservice US-AB

ISBN 978-91-7549-687-0

Home care for patients in need of advanced care and technology - a challenge for patients and their caregivers

Thesis for doctoral degree (Ph.D.)

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“For the things we have to learn before we can do them,
we learn by doing them”

Aristotle, The Nicomachean Ethics

Michael,
My beloved husband and companion for life.
When I need you, you're always there. Thank you!

Daniel and Johanna,
My dearest children who fill my heart with joy.
Remember - always follow your dreams!

ABSTRACT

Background and aim: There is an ongoing trend of advanced care 'moving out' from hospitals and into patients' homes. In Sweden, caregivers with limited training, employed by municipalities or private agencies take 24-hour responsibility for patient care with limited support from healthcare professionals. The aim of this thesis was to explore and gain new and broadened understanding of 24-hour home care for patients in need of advanced care and technology.

Material and methods: A multi method approach was used. Studies I and II resulted from a field study using grounded theory methodology. Interviews and observations were performed in the homes of four adult patients in 24-hour home care (study I) and their 19 caregivers (study I and II). Participants in study III and IV were caregivers (n=128) caring for adult patients in 24-hour care with home mechanical ventilation (HMV). A study-specific questionnaire, including questions in accordance with the Demand-Control model, was used. Caregivers' socio-demographic and workplace data, perceived competence and responsibility (study III), and their perceived working conditions (study IV) were investigated. Descriptive statistics and logistic regression analyses were performed. A comparison was conducted with a population-based survey including caregivers in general home care (n= 585).

Results: In the qualitative studies, patients and caregivers were found using compensatory processes when care and work were not suited to their needs, illustrated in two theoretical models: 1. The patients strived for control and safety by *taking control, seeking safe hands* and *navigating in the care system*. In their strivings, they selected caregivers they could trust, instructed unskilled caregivers and coordinated their care themselves. 2. The caregivers compensated by *day-by-day learning, balancing relations with the patient, self-managing* and *navigating the patient care system* in their strivings to combine safe care with good working conditions. Actively employing compensatory processes, some caregivers adopted an 'inclusive approach', compensating for their own barriers as well as those of their colleagues, and taking overall responsibility for their workplace. Among the caregivers in HMV care (n=128) investigated, 55% (n=70) lacked formal health care training. 27% (n=34) reported shorter courses, and 19% (n=24) had training equivalent with a licensed practical nurse exam (LPN). Regardless, 80% the caregivers rated their competence as high, and 59% rated their responsibility as high. *On-the-job training* was significantly associated with high ratings on perceived competence, responsibility and control. Being *clinically supervised* was associated with high ratings on responsibility and psychological demand. Seventy-six of caregivers intended to stay in their jobs for the next two years, and 29% experienced bullying and/or discrimination at their workplace. Female caregivers had more healthcare training and felt more competent and stimulated than males. Compared to the population-based survey group, no differences in perceived working conditions were found except for psychological demand, where the caregivers in HMV care rated lower.

Conclusion: Despite a general lack of formal healthcare training and support, patients and caregivers managed 24-hour home care by *compensating, on-the-job training, one-patient care,* and *including caregivers.* However, the results suggest that improved training, support and quality control are needed to ensure safe patient care and good working conditions for caregivers. These results can contribute to continued development of the caregiver role in HMV care.

Keywords: Home care, caregiver, home mechanical ventilation, competence, training, responsibility, working conditions

LIST OF SCIENTIFIC PAPERS

This thesis is based on following original articles, referred to in the text by their Roman numbers:

I. Swedberg L., Hammar Chiriac E., Törnkvist L., Hylander I.
Patients in 24-hour home care striving for control and safety.
BMC Nursing 2012; 11:9. doi: 10.1186/1472-6955-11-9.

II. Swedberg L., Hammar Chiriac E., Törnkvist L., Hylander I.
From risky to safer home care: Health care assistants striving to overcome a lack of training, supervision, and support. International Journal of Qualitative Studies on Health and Wellbeing 2013; 8: 20758.

III. Swedberg L., Michélsen H., Hammar Chiriac E., Hylander I.
On-the-job training makes the difference: Health care assistants' perceived competence and responsibility in the care of patients with home mechanical ventilation. Scandinavian Journal of Caring Sciences 2014; doi: 10.1111/scs.12173.

IV. Swedberg L., Michélsen H., Hylander I.
Perceived working conditions among health care assistants caring for patients with home mechanical ventilation. Submitted.

CONTENTS

LIST OF ABBREVIATIONS

HC assistant	Health Care assistant (a common title for caregivers used in the studies).
HMV	Home Mechanical Ventilation
HMV care	Home care when patient is treated with HMV
ICU	Intensive Care Unit
HC professional	Health Care professionals, i.e. nurses, physicians, physiotherapists, dieticians etc., employed in primary, specialist and municipality care and may delegate medical tasks to the caregivers.
RN	Registered Nurse, both in specialist care and primary care
LPN	Licensed Practical Nurse
GT	Grounded Theory
GTM	Grounded Theory Methods
JDC-model	Job-Demand-Control model
JD-R-model	Job-Demands-Resources model
OR	Odds Ratio

Definitions used

Patient	An adult person in need of home care including advanced care and technology, requiring 24-hour care by one or more employed caregivers.
Caregiver	The direct carer employed in municipality or private agency to deliver 24-hour home care. Other titles are personal assistant, care assistant, carer, nursing assistant. In this thesis, the terms caregiver and HC assistant have identical meaning and will be used synonymously and where appropriate.
Home care	Care provided in the home by employed caregivers, including support with ADL (Activities of Daily Living) and health care. Responsible authority is the municipality.
24-hour home care	Home care when caregivers are required around the clock;

	due to care needs and/or needs of surveillance.
Primary care	Patients' primary outpatient contact with HC professionals, i.e. district nurse, family physician, physiotherapist etc. Often organised in a primary health care centre located in patients' geographical housing area. Responsible authority is the County Council.
Specialist care	Hospital-based care, inpatient and outpatient. HMV clinics for patients treated with home mechanical ventilator are included. Responsible authority is the County Council.

1 INTRODUCTION

There is an on-going global and national trend where advanced care is seen moving out from hospitals and into patients' homes. The rapid development in medicine and technology does make it possible for patients with advanced care need to remain at home, however with great challenges concerning how to organise their daily care [1]. One example is the care for patients with breathing impairments in need of home mechanical ventilation (HMV), a care often considered complex with the need of special trained nursing staff normally found in intensive and acute care hospital settings [2]. My special interest on the transition from intensive care to home care for patients with advanced care needs has been a 30 year journey and my career as a nurse and a clinical teacher has taken me to different countries and different health care systems. As a young nurse in Baltimore, USA, I was confronted with difficulties when discharge planning a patient with tracheostomy with advanced needs such as suction of airways for safe care. The hospital was the well-known John Hopkins Hospital with excellent care, but the patient was homeless and could expect no home care which would diminish his chances for survival. I was stunned over the lack of support to the poor man! Back in Europe, I got the opportunity to live and work in Denmark where I experienced a good chain-of-care for patients' leaving the hospital with HMV. Several years later, now back in Sweden and a clinical teacher in intensive care, my curiosity deepened concerning competence in home care and patient safety. Patients with HMV were discharged to their homes to be daily cared for by caregivers with limited healthcare training. How was that possible? My initial research question was now ready to be formulated: What were the experience/s receiving (patients) and delivering (caregivers) advanced care in the home setting, far away from professional competence and support? And how did patients and caregivers manage? The rationale for this thesis is to contribute to a better understanding of home care when advanced care and technology is involved from the perspective of adult patients and their direct caregivers. The focus for the thesis is patients' and caregivers' experiences of home care, and caregivers' perceived working conditions.

2 BACKGROUND

There is a growing number of patients with substantial care needs being treated in their homes, blurring the boundaries between hospital care and home care [3]. The increasing needs for home care for medically fragile patients, who are often dependent on technology and in need of care and surveillance around the clock, have been described as challenging [1]. Home care solutions are important not only for health, social and emotional benefits but also for optimising the use of public expenditure as home care has been shown to be more cost-effective than institutionalised care [5].

2.1 HOME CARE

2.1.1 Definitions

In a general sense, the meaning of home care, as opposed to hospital care, is quite uncomplicated, meaning that care is delivered in the patients' own home. Home care may range from care for persons who only need help occasionally with domestic aid to persons with complex and continuous care needs. When 'mapping professional home care in Europe', a project funded by the EU, the definition used was: Professional care, provided at home to adult people with formally assessed needs, which includes rehabilitative, supportive and technical nursing care, domestic aid and personal care, as well as respite care provided to informal caregivers [6]. However, home care systems appear to differ both between and within countries [6]. Therefore, to understand the consequences of home care, with regards to organisation, responsibility and financing, a national definition must be sought.

Home care is broadly defined in the term base of the Swedish National Board of Health and Welfare as care and social service delivered in a persons' own residence, or an equivalent housing. Within this broader definition of home care, a distinction is made between home assistance operated by the municipalities, and home health care, operated by the county councils. Home assistance is service with daily living, i.e. practical help with cleaning, shopping and cooking, and personal assistance, with the help to meet physical, psychosocial and social needs, i.e. help with personal hygiene, mobilisation and socialisation.

Home health care is health care when it is provided in the patients' own residence, or an equivalent housing, and where the responsibilities for the medical procedures are continuous over time. [7]. These definitions by the Swedish National Board of Health and Welfare are used in this thesis.

2.1.2 Swedish home care organisation

The responsibility for the Swedish health care is regulated by law and divided between the state, the 20 county councils and 290 municipalities [8]. Swedish public policies promote well-being, access to good health care and social services, as well as the possibility to live independently and safely at home, despite old age or caring needs [9, 10]. To accomplish

these goals resources have been transferred from acute hospital care to community care. The number of hospital beds and the length of hospital stays has decreased to around half since the early 1990s [11], making home care more important and complex than before and in need of continuous improvements [1]. There are known difficulties in describing the Swedish home care organisation as well as comparing activities within the area due to regional differences as well as an inconsistent use of terms and contents [1]. The county councils are responsible for medical health care and are largely divided into hospital care, specialist care included, and primary care. The primary care is the basis of health care services irrespective of disease, problem and age, and is the biggest part of healthcare services in Sweden. The municipalities are responsible for services and assistance (home assistance) in patients' homes or in special accommodations such as nursing homes [12]. Since 1992, when municipalities took over parts of the responsibility from the county council for health care in special housings, medically responsible nurses (MAS) have been employed by the municipality for quality control and patient safety [13]. Patients with substantial care needs often have several care providers, and therefore have to rely on collaborations between the local municipality responsible for the daily care at home, and several actors within primary as well as specialist care with authorizations from the county council [14, 15].

2.2 24-HOUR ADVANCED HOME CARE AND TECHNOLOGY

2.2.1 Social laws for financing 24-hour home care

Swedish health care is largely financed by public tax and regulated by law with aims to provide good and equal health care for all citizens [10]. However, current national social laws divide persons with substantial care needs with a wish to remain at home into two groups by age, including different opportunities for 24-hour home care [16, 17]. The LSS act [18] regulates support and service for persons with certain functional impairments due to mental impairment, and, due to long-lasting physical or psychological impairments not caused by the normal ageing processes, respectively. Examples of the last category are persons at all ages with substantial care needs due to illness or trauma in need of continuous assistance for their daily living [18]. The amount of care needs are assessed prior to agreement on a financing plan, where the municipality finances care costs up to 20 hours per week and the Swedish Social Insurance Agency the costs above 20 hours per week. In addition, the county council may co-finance if there are special needs of health care as well [19], however great regional and local differences exist. Approval of support and service according to LSS [18] will make the person eligible to choose between care providers, including municipalities, private agencies, or even become the employer him/herself. With this solution, a work group with 'designated caregivers', i.e. caregivers scheduled to work for the specific patient, will be organised [20]. As a contrast, persons over the age of 65 years are not eligible to apply for support and service according to LSS 9b§ [18] (however if receiving personal assistance up until age 65, they may continue with the service also after the age of 65). Persons over the age of 65 are instead covered by SoL [21], an act for the elderly which includes home assistance

with the use of intermittent home visits. When caring needs exceed offered home assistance, a special housing arrangement (nursing home) will be the normal solution offered to the person. These age discriminatory regulations limiting the access to home care for persons 65 years and older with substantial care needs has been addressed previously [16, 17].

2.2.2 Basic, advanced and technical care

2.2.2.1 Basic and advanced home health care

Patients with substantial care needs often have a mix of needs leading to several constellations of care providers. Firstly, there is a clear distinction between basic and advanced home care on an organisational level. Basic home health care; i.e., health care provided in the home of a person who does not need specialised palliative care, inpatient care, or advanced care at home, may be performed by HC professionals in primary care [22, 1]. In basic home health care, the district nurse is the common medical provider, thus a good collaboration between her/him and the responsible family physician is important, also described by Modin et al. [23]. Advanced home health care, on the other hand, is provided by HC professionals, often mobile teams based at a hospital. Traditionally, advanced home health care has focused on palliative care and support, however in later years, patients with chronic substantial needs may be enrolled in this service as well [1].

2.2.2.2 Role of the caregiver

The patients in need of 24-hour home care often have conditions which make them in need of several medical procedures daily, normally performed by HC professionals. Examples are administration of medication, parenteral nutrition, stoma care and handling of technology [24]. As per routine and according to current regulations [25], caregivers employed by the municipality (or a private agency) and not formally trained, may be delegated to perform these tasks by district nurses or other HC professionals [26]. The delegation is a multifaceted task, and the HC professional needs to be assured of the caregivers' knowledge prior to delegation. In a study by Craftman et al. [27], district nurses, frustrated due to lacking in time for important training of the caregivers prior to delegation of management of medication, identified knowledge gaps which could endanger patient safety and quality of care. The practice of self-care [28], i.e. that the patient can perform medical tasks him/herself, or with the assistance to self-care from family or caregivers, has been introduced in some regions as a substitute to delegations [11].

2.2.2.3 Technology in home care

The use of medical technology in home care has increased in most industrialised countries, minimising differences in care received in hospitals from that of homes [29]. A medical device is a product approved for home use to diagnose, prevent, monitor, treat or alleviate diseases, or compensate for an injury or disability [30]. Commonly used medical home devices include ventilators, pumps for parenteral nutrition, peritoneal dialysis, oxygen therapy and equipment for secretion clearance [29, 31, 32]. The use of technology in home

care often requires specialist knowledge and skills for appropriate use, and all persons involved, patients, family and caregivers, must have adequate knowledge in proper safe handling to prevent injuries [29, 1]. By user-friendly technology and self-care, patients may take control over their own health-related issues, thus increasing perceived autonomy [31]. If there are caregivers employed, there is the managers' responsibility to organise the work to facilitate a safe use of medical devices and ensure that the personnel are adequately educated [32]. The technology may facilitate treatment and decrease caregiver' workload, but may complicate their work as well, if the devices are difficult to handle and not completely trustworthy [33]. District nurses in palliative home care, studied by Munck et al. [34], experienced vulnerability caused by the increased use of medical devices, and requested more training and support. Homecare technology, particularly when life-support devices such as ventilators are involved, calls for caregiver training on technical knowledge as well as specific care procedures, such as airway clearance in order for caregivers and their family to feel secure and satisfied [35, 36, 37].

2.2.3 Patient safety in home care

Homes are not designed for receiving or providing healthcare services rather they are designed for living. Risks exist in all health-care settings; however, private homes lack the uniformity that exists in hospital environments, making home care safety uncontrolled and unregulated [38]. According to Lang, patient safety in home care is further complicated by the fact that patients often make decisions about managing medications and treatments while clearly recognising that these decisions are not always congruent with the recommendations from their care providers [39]. Yet another complicating factor is the high reliance upon untrained family and caregivers in home care, which adds complexity and clearly differentiates home care from acute care [39]. In a review by Masotti et al. [40], 168 studies on adverse events in home care were studied. The events were mostly related to medication errors, infections, falls and failures associated with the use of technology, e.g. oxygen therapy, ventilators, dialysis and equipment/computer operational failures. One older study by Srinivasan et al. [40], reported events associated with home ventilators to 189 events per 150 patients in one year. The home environment may also affect caregiver safety as well. There is a known lack of research and knowledge in home care safety on a broader perspective [40]. Patient safety in Swedish healthcare is currently monitored closely [41], however, reported adverse events in the annual reports are not detailed enough to allow further analysis at the level of specific patient- or workgroup to link adverse events within, e.g. home care or HMV care [42].

2.3 THE PATIENTS

2.3.1 Home mechanical ventilator care (HMV care)

2.3.1.1 Prevalence data

Since nearly 30 years, there are various possibilities to treat patients with prolonged breathing impairments with the use of ventilators suited to home settings [2]. Advancements in medical

technology and the positive trends of home care have increased the number of patients being treated with home mechanical ventilation (HMV) globally [43]. Common definition for HMV is non-invasive ventilation (via facial/nasal mask) or ventilation via a tracheostomy (opening in trachea) for a period of >3 months on a daily basis carried out mostly in the patients' home or at other long-term care facilities, excluding hospital care [43]. Use of CPAP (continuous positive airway pressure) in treatment of sleep apnoea is not included in the definition of HMV. The estimated average prevalence of HMV in Europe, with 16 European countries surveyed, was estimated to 6.6 per 100 000, with great variations between the countries [44]. There are difficulties to interpret data due to known incomplete reporting [4, 44]. In Sweden, approximately 2500 patients were 2013 registered using HMV [4], with the estimated prevalence for adults 26 per 100 000 inhabitants. Common diagnosis groups among adults in need of HMV are OHS (obesitas-hypoventilation syndrome), neurological degenerative diseases (ALS, Duchennes syndrome), tetraplegia due to high spinal cord injuries, and tumours in the head and neck region [4]. However not registered, some patients may use their HMV without any support, thus adopting self-care [31] while others are in need of full support by one or more caregivers, either because of a total lack of own respiration, because of other physical impairments, or a combination of both [4].

2.3.1.2 HMV care organisation

HMV is seen as a successful approach to reducing incapacity and mortality and to enhancing quality of life [45, 46, 47], however there are known challenges in the transition from hospital to home [48]. Patients with breathing impairments requiring mechanical ventilation are typically cared for in ICU (intensive care units) or, when available, in specialised weaning clinics for prolonged care or preparations for discharge to home [49]. Swedish RNs, not specialised in intensive care, anaesthesiology or specific HMV care, usually hesitate to care for patients with breathing problems due to perceived lack of competence. There is a known lack of step down opportunities for patients preparing for HMV care, affecting the individual patient who may have to remain in ICU longer than needed, as well as the total bed capacities and costs for ICU care [50]. Patients and families need proper support in the transition from hospital care to the life at home [51, 52, 53] including sufficient caregiver competence prior to discharge to feel safe. However, several studies concerning patient and family experiences on HMV care point out insufficient caregiver competence as one of the most concerning issues [51, 47, 35, 54]. HMV clinics, hospital or outpatient units that initiate or prescribe HMV and/or co-ordinate HMV services, are therefore needed [44] for proper training and support.

2.3.1.3 HMV care in Stockholm County

Patients in HMV care living in Stockholm County may be enrolled in one of two current HMV clinics for follow-up and out-patient care. Patients with invasive HMV (with use of tracheostomy) are usually enrolled to NRC (National Respiratory Centre), a hospital-based clinic located in the northern Stockholm, whereas patients with non-invasive HMV (with use of facial/nasal mask) may be enrolled to the HMV centre at the department of neurology,

located in the southern Stockholm. Patients with non-invasive HMV may also be enrolled to the department responsible for their main diagnosis, e.g. pulmonary. All medical devices needed for HMV care, e.g. ventilators, suction devices etc., are leased and serviced from one of two main distributors in the region. The service is regulated by law and state financed [10]. Prevalence data for Stockholm County, according to a recent report on the status of HMV [55], is 440 patients (all ages) registered with HMV, and of them approximately 80 adults with invasive HMV and in the need of 24-hour home care, most often with the use of caregivers according to LSS [18]. Total costs (for state, municipality and county council) were estimated to 370 million SEK (40 million euro) per year [55]. Beside patient care and follow up, the two HMV clinics have the responsibility in training patients, family and caregivers in HMV related issues prior to discharge to home. NRC also has the mandate, from the county council, to train and delegate caregivers working in invasive HMV care in Stockholm County, as well as do follow-ups [55].

2.4 THE CAREGIVERS

2.4.1 Paraprofessionals in home care

The caregivers in Swedish 24-hour home care are commonly employed by the municipality to perform one-to-one care on a daily basis, with or without the accompanying of family caregivers. On the request of the patient, a private staffing company may take over the service of caregiver employment and supervision from the municipality [56]. In the literature, caregivers in home care are often described as paraprofessionals and defined as carers with limited health care training, not being members of a profession and working semi-autonomously under the direction from HC professionals [57, 58]. The increased demand on home care service worldwide has forced several countries to focus on issues regarding how to attract, recruit and make caregivers stay in their positions [3, 59].

2.4.2 Caregiver competence

2.4.2.1 Formal training

Currently, there are no formal competence requirements or qualifications for the caregivers in Swedish home care issued by the authorities [60, 20]. However, National Board of health and Welfare [11] recommend a formal training equivalent with the national secondary school program in health and social care for a licensed practical nurse (LPN) examination [61, 62]. In recent years, recommendations have also been outlined for specific groups of caregivers active within care of the elderly [63] and the functionally disabled [64]. Separate courses on a secondary school level within health and social care are mostly offered through adult educational programs operated by the municipalities or private education companies [60]. Due to a lack of registry of privately employed caregivers, there is no complete Swedish registry, nor a database regarding caregivers work organisation or competence levels [65]. Problems with lack of formally trained caregivers in home care are recognised by the authorities [56, 1] and also described by others [66, 67]. Several states in the US have requirements for certifications of caregivers in home care, however there are known

difficulties in compliance with them [59]. A contrary aspect of formal training, is that patients with HMV have shown ambivalence to healthcare trained carers, as they feel 'hospitalised' with too much focus on nursing and healthcare instead of active life and well-being [53].

2.4.2.2 Informal training

Informal training in the home care sector is well described in the literature [53, 68, 69]. Caregivers in home care usually receive informal training by their employer, often as short introductory courses in general topics such as ergonomics, hygiene routines and work ethics [60, 20]. Depending on the patients' care needs and the practice used on delegation, additional training may be offered by HC professionals, e.g. in administration of medication, parenteral nutrition, stoma care and handling of technology [24, 70]. The introduction to the workplace is often performed by working in parallel, i.e. when the newly employed caregiver works with a colleague to learn routines and procedures [71, 72]. However, learning from colleagues who themselves lack in formal training may cause inappropriate training, thereby perpetuating poor care practice [73]. Due to the lack of regulations and registry, large geographical differences may exist, in training content, the use of continuous training as well as in length [60, 20].

2.4.3 Caregivers' working situation

2.4.3.1 Doing professional work in a private home domain

Home care, for the caregiver, has been described as a balancing act between the professional work and the private home domain which may be rewarding but also challenging [74]. By the conditions of employment, the caregiver is obliged to follow professional guidelines and directions from managers and HC professionals, similarly to working in institutions and hospitals. However, in the private home domain, the caregiver is also obliged to follow patients' rights to decide for him/herself. Struggles to fulfil orders from managers, HC professionals as well as the wishes and needs of the patient in order to meet the needs of several parties is previously described [75]. The home care organisation promotes individualised care because the caregiver may focus at one patient at the time [76]. However, difficulties accompanied with becoming too close in the relation to the patient are described [20].Traditionally, home care is characterised by lonely work being one known risk factor, however organisation for 24-hour home care often include the formations of workgroups with up to 20 caregivers for each individual patient, instead raising issues on group roles and processes [77] as well as formal versus informal leadership [78, 79].

2.4.3.2 Known challenges

With no authorisation, Swedish caregivers assume a considerable amount of responsibility for the direct care and safety of their patient. Also, with HC professionals located at distance, caregivers need to cope with complicated care situations much by themselves. The caregivers' working situation is complicated due to the home setting as well as the organisational structures, which may result in stress-related problems and high turnover rates

[20, 80, 81, 82, 83], lack of adequate training for their tasks [73, 68], lack of control while working in a patients' home [75, 84] and low status and pay [85] are already known factors. The Swedish Work Environment Authority [86] identified several risk factors for caregivers in home care, such as insecure employments, lack of training, social isolation and conflicts with patients and family, and emphasise employers' responsibility to comply with existing laws protecting the caregivers [87].

2.5 THEORETICAL FRAMEWORK AND CONCEPTS

2.5.1 Working conditions in terms of job strain and job resources

2.5.1.1 Job Demand-Control model

It is previously known that health care workers are at risk for high job strain and impaired well-being due to a high workload combined with emotionally stressful interactions [88, 89, 97]. A leading model used in research on working conditions and employee health is the Job Demand–Control model (JDC-model) of job strain [90, 91], based on two psychosocial job characteristics. The first characteristic includes job demands conceptualised as psychological demands such as working under time pressure and coping with complex, mentally demanding tasks. The second characteristic relates to the degree of control employees have over their daily work. The JDC- model core hypothesis suggests that high levels of psychological demand combined with low levels of job control are related to adverse health effects, e.g. work-related stress [92], burnout [93] and a risk of cardiovascular disease [94]. Additional work by Johnson and Hall [95] and Karasek and Theorell [91] added work-related social support to the model, as it had been noted that support received from managers and co-workers buffered the effects of high demands and low control.

2.5.1.2 Focus on job resources in health care

In later years, studies on job strain and stress among healthcare workers [88, 97] are found referring to the Job Demands-Resources model (JD-R-model) [96], outlined by Bakker and colleagues [98]. The JD-R-model proposes that employee well-being is related to a wide range of workplace characteristics that can be conceptualised as either job demands (e.g. aspects of the job that require sustained physical or psychological effort) or job resources. Job resources refer to health-protecting factors and can be defined as organisational aspects of work that are functional in achieving work goals, reducing the effect of job demands and their accompanying psychological strain, and stimulating personal development [98]. Dollard et al. [99] reviewed 35 studies within health and community care and found low job control, low support, low rewards, role stressors, interpersonal conflicts and low organisational justice as major source factors associated with healthcare workers' distress.

2.5.2 Job resources in 24-hour home care

2.5.2.1 Workplace learning

There are several theories with focus on practical training, continuous training and adult learning, focusing on the workplace [100]. According to Matthews [101], the workplace is merely a physical location but should be understood to also include shared meanings, behaviours and attitudes that determine the working environment and relationships. Work-place learning follows the principles of adult learning, thus it should be in its context, related to the learners' needs, directly applicable, practical and preferably accompanied with the opportunity of reflection [102]. Further, adult learning is often stimulated following the identification of a competence gap. Manley et al. [103] defined their concept of work-based learning as a process that concentrates on how learning takes place within the workplace, and is stimulated by workplace activities that engage the learner in discussion and debate with workplace colleagues. Wilkinson and Walsh [104] defined workplace-based learning in the medical field by the terms 'learning on the job', meaning learning while in an uncontrolled healthcare situation, and ' learning at the job', describing controlled activities such as meetings and peer-review activities. This is well in line with well-established concepts of learning, originating from Dewey's' [105] 'learning by doing' as well as to Schön's [106] definition of 'reflection-in-action' as opposed to 'reflection-on-action', sometimes described as 'thinking on our feet' and including the use of own experiences and feelings in building new understandings [106]. The reflective practice, as outlined by Schön [106] is widely used in nursing education as a key concept in life-long learning and personal development [107]. Workplace learning may also be described by the characteristics of situated learning, outlined by Lave and Wenger [108], that learning takes place in the same function, context and culture in which it occurs and with social interactions and collaboration as essential components. Recent studies, describing workplace learning received by caregivers, have shown positive effects on their perceived competence and job satisfaction [109, 69, 68, 67].

2.5.2.2 Support

An important job resource, according to Bakker and Demerouti [98], is social support, meaning work-related support from managers and colleagues. Numerous studies have been conducted in the field, however there are several contradictions found which point at the known difficulties in defining and measuring perceived support [98]. Studies on employee health have suggested the need to also include different types of support on group and organisational levels, thus broadening the perspective of support [110], and general programs to this end have been developed for the health care sector by e.g. Cox et al. [110] and implemented by e.g. Michélsen et al. [111].

Despite those difficulties, there are several indications in the literature describing the importance of social support for caregivers in home care, on their increased job satisfaction [89, 112, 113] improved empowerment [57] and decreased job demand [114]. Besides the need of social support, several studies described the need of caregiver and patient support

from HC professionals as well, particularly seen in palliative home care [83, 73] and in HMV care [115, 47].

Clinical supervision has been introduced as an educative and supportive method of enhancing the quality of care and restoring well-being at work in nursing [116, 117]. Today, there are several models of clinical supervision, with learning and change through self-reflection seen as core mechanisms, that are sufficiently well developed to be regarded as comprehensive and empirically testable [118]. According to the reflective practice as outlined by Schön [106], clinical supervision may be viewed as a reflection-on-action, i.e. when talking things through with a manager or colleagues, which enables the supervisees to spend time exploring why they acted as they did, what happened in the group, etc. [106]. In a study by Koivu et al [119], nurses who received clinical supervision reported more job satisfaction and were more motivated and committed to the organisation than their peers. Even if scientific evidence on the effects of clinical supervision is scarce, it is largely accepted that employees who are supported and are allowed time to reflect and develop will make a significant contribution to patient well-being and safety [117]. Devlin and McIlfatrick [83] emphasised the need for supervision of caregivers in palliative home care, and the importance to combine supervision with workplace training in the care of elderly has been described by Häggström [120] and Fläckman [121].

2.6 KNOWN CHALLENGES IN 24-HOUR HOME CARE

In summary, there are some known challenges to 24-hour home care. Home care is becoming more popular to patients as well as to society, and also more medically and technically advanced, which makes managing their care challenging. Research suggests that caregiver competence is of great concern for patients in need of trained caregivers due to their advanced care needs, including technology. In spite of that, Sweden has no current formal requirements for work in 24-hour home care, HMV care included. Also, there is a known lack of quality control, which is considered standard in other areas in healthcare, potentially jeopardizing patients' safety as well as the caregivers working conditions. Particularly, caregivers' special working conditions are challenging, doing professional work in a private home oftentimes with only limited support from HC professionals. These challenges to 24-hour home care, prompted my interest in a closer investigation of how patients and caregivers experience the care received and given, and to study what conditions could potentially be improved for a better and safer care and for a professional development of caregivers.

3 AIMS

3.1 GENERAL AIM

The general aim of this thesis was to explore and gain new and broadened understanding of home care for patients in need of advanced care and technology.

3.2 SPECIFIC AIMS

To gain new and broader understanding of patients receiving 24-hour home care by constructing a theoretical model to illustrate their main concern (I).

To explore caregivers' experiences and management when delivering 24-hour home care to patients with substantial needs (II)

To investigate socio-demographic and workplace background factors among caregivers, working with patients in need of 24-hour home care due to home mechanical ventilation (HMV) and other advanced caring needs (III-IV).

To describe and analyse perceived competence and perceived responsibility among caregivers, working with patients in need of 24-hour home care due to HMV and other advanced caring needs, adjusted for socio-demographic and workplace background factors (III).

To describe and analyse perceived working conditions among caregivers caring for HMV patients in terms of psychological demand, control, stimulance, social support and working environment (IV).

To compare the studied group of HC assistants with a population-based survey including caregivers, regarding their working conditions in terms of perceived psychological demand, control and social support (IV).

4 MATERIAL AND METHODS

4.1 STUDY DESIGN

This thesis includes four studies carried out in the period of 2007-2012 (Table 1). A multi-strategy approach was used throughout the research process in terms of its rationale as well as its practise. Firstly, a qualitative, inductive approach was needed to gain new and broadened understanding regarding the research aim, resulting in two qualitative studies (studies I and II) derived from the same field study using Grounded Theory Methods (GTM) [122, 123]. By using the field study technique and collecting data from multiple sources, findings are enhanced according to classic grounded theory [124]. Secondly, findings from the qualitative studies were supplemented by two studies (studies III and IV) derived from the a cross-sectional questionnaire study. The mixed-method study design was selected to enhance the completeness and credibility of the findings in this thesis [125].

Table 1. Overview of the general study designs of studies.

Study	Design	Data collection	Analysis	Participants	Aspects studied
I	Qualitative	Field study observations and interviews	GTM	4 patients and 19 caregivers	Exposed states and strategies for safe care
II	Qualitative	Field study observations and interviews	GTM	19 caregivers	Barriers and strategies for safe care and good working conditions
III	Quantitative	Questionnaire	Descriptive statistics Logistic regression	128 caregivers	Perceived competence and perceived responsibility
IV	Quantitative	Questionnaire and comparison survey data	Descriptive and analytic statistics	128 caregivers and comparison data (585 caregivers)	Perceived working conditions

4.2 STUDY I AND STUDY II

4.2.1 Grounded Theory (GT)

4.2.1.1 Background

The discovery of GT was made by the American sociologists Barner Glaser and Anselm Strauss when they in the 1960s presented a systemic process for qualitative social research [122], initially with their study of dying patients in *Awareness of dying* [122]. Glaser contributed to the structure in methodology with his statistical background, and Strauss with his previous qualitative analytic work when connected to sociology research at the University of Chicago. Through Strauss, GT was influenced by symbolic interactionism, a theory to understand society and human behaviour through the meaning of events and the symbols people use to convey those meanings [126]. Their collaboration ended and since then, there has been an ongoing debate between Glaser's more classic GT, emphasizing conceptualisation [124, 122] and Strauss and Corbin's [127, 128] more descriptive approach. There are now several variations of GT. Charmaz [123] presented a more interpretive and constructivistic approach to GT in "Constructing GTM" with the focus on writing about understanding phenomena rather than explaining them. Contrary to the classic GT view on data as objective, Charmaz also argued that theoretical findings should be regarded as a construction by the researcher in interaction with data. She further argued that GT should be used as a flexible and systematic tool to gather and analyse empirical data, and introduced the term grounded theory methods (GTM) to include the variations in the approaches [123].

4.2.1.2 Main characteristic of GTM

GTM is a methodology involving conceptualization of empirical data and systematic abstraction. GTM consists of systematic, yet flexible guidelines for collecting and analysing qualitative data to construct theories 'grounded' in data, preferably from several sources [122, 123]. The GTM procedure, where data collection and analysis are parallel processes, includes the initial coding of data followed by a structured sorting of categories and subcategories. The constant comparative method is the ongoing process of analysis, comparing data with emerging codes, codes with categories, and categories with categories, to explore differences and similarities. Unique for GTM is the possibility to return to the field sites (data sources) during analysis for gathering more data to check and refine categories. The outcome of a GTM study is a substantive theory that may explain an event or phenomenon in terms of a basic social process [129]. According to Glaser, the theory could further be tested by using both qualitative and quantitative methods [124].

4.2.2 The position of this thesis in GTM

GTM was chosen because of my interest in generating theory and concepts about social processes in the participants' natural setting, in this case interactions in the home care situation. There is a great variety of GTM with different, however overlapping, guidelines on how to proceed in the research process [130]. According to Hallberg [129] it is therefore important to clearly state approaches chosen for the process of analysis in GTM. In positioning this thesis, I followed the methodological principles of classic grounded theory [124, 122] concerning multiple data sources, theoretical sampling, conceptualisation and

theory generating, following steps used by Hylander [140]. However I do recognise the roots in symbolic interactionism [126] and therefore rely on a constructivistic approach regarding ontology as described by Charmaz [123]. As a researcher I cannot totally free myself from interpreting data, thus basic social processes illustrated through theoretical models in this thesis should be regarded as a construction by the researcher in interaction with data [130].When it comes to the coding process, I have followed the terminology from classic GT, using open coding and theoretical coding. But instead of the term selective coding, I have chosen the term focused coding in line with Charmaz [123]. The reason for this is the controversy between Glaser versus Strauss and Corbin around that term and the following confusion [130].

4.2.3 Field study

The unique characteristic of the field study approach is that the researcher collects data in the participants' natural setting and uses more than one data collection method, one of which is usually observation [131, 132]. My intention to gain new understanding on home care included the patients and caregivers experiences as well as their actions, i.e. their interactions in care situations. By using data from both perspectives, the respondents' words 'what they said' and their actions 'what they did', the findings were broadened and strengthened.

4.2.4 Research setting

The field study was performed in a mid-sized municipality in Stockholm County, Sweden over a period of two years (2008-2009).

4.2.5 Participants and settings

The field study was conducted in patients' homes and the sample consisted of four patients and 19 caregivers (with the term HC assistants used in publications) (Table 2.). The inclusion criteria were: Adult cognitive intact patients, in need of 24-hour home care by employed caregivers due to substantial needs, basic as well as advanced. End-of-life care was excluded. In the enrolment process, a manager at the local municipality was approached for assistance with selection of suitable participants and for arranging a first contact. Prior to enrolment, the author visited the patient and gave oral and written information about the study and ensured confidentiality. When patients' written consent was obtained, the author gave oral and written information to the employed caregivers on a planned staff meeting. Patients and caregivers were assured they could decline participation anytime. The visits by the author during the field study period were discussed and approved by the patient, with oral consents obtained prior to observations of participating caregivers. Written consents were obtained by caregiver prior to face-to-face interviews. The variation in data was optimised by visiting each patient on several occasions at different times of the day, which enabled several caregivers to be observed.

Table 2. Data sources studies I-II (patients n=4, caregivers n=19).

	Setting[1]	Patient characteristics		Caregivers		Observation time
	No.	age	sex	Interviewed and observed (n)	Observed only (n)	(hrs)
	1	75	female	1	3	20
	2	25	male	4	4	30
	3	70	female	4	0	20
	4	62	male	3	0	8
Total	4			12	7	78

[1] Home of patient

The patients (n=4) included in the study were all immobilised due to neurological or neuromuscular diagnosis/symptoms and in need of full help from one or two caregivers in care situations (range 8-17 caregivers per patient). All mobilisations needed use of electric hoists, chairs and beds. Two patients needed help at meals and two patients used tube feeding (enteral nutrition). All patients needed help with administration of medication. One patient needed oxygen via mask and oral suctioning of secretions. One patient needed home mechanical ventilation 24-hours via tracheotomy and used several pieces of home care technology equipment. Of the four patients, one patient used lip read for communication whereas the other three could communicate verbally. There were no family members living with the patients during the data collection.

A majority of the caregivers were females (n=17) with the average age of 36 years (ranging 20-53 years); 12 were interviewed and observed and 7 were observed only. All caregivers were employed by the municipality and their educational background varied from a LPN-exam (n=3) to shorter courses and/or employer-supplied training (n=16). The shorter courses included care of elderly and personal assistance while the employer-supplied training mostly consisted of introductory days covering topics such as hygiene and ergonomics. The caregivers performed basic care autonomously and advanced care under the direction of HC professionals, in form of delegated tasks. Administration of medication and tube feeding were delegated by the district nurse and in the care for the patient with home mechanical ventilator, a HMV clinic was responsible for training and delegation of the caregivers. However, due to a high turnover rate, several of the HC assistants in the study reported that they did not have the above-mentioned training or delegations.

4.2.6 Data collection

Data was collected by the author using face-to-face interviews and field observations (78 hours on 17 occasions) over a period of two years (2008-2009). *The face-to-face interviews* with patients and caregivers, 20 to 60 minutes in length, followed a semi structured guide with open-ended questions (Attachment 1): The patients were asked to describe experiences and feelings regarding own care needs, decision-making, relation to caregivers, contacts with HC professionals and areas of improvement, and the caregivers were asked to describe experience and feelings regarding patients' care needs, own working conditions, relation to patient and colleagues, contacts with HC professionals and areas of improvement. All interviews were performed in the homes of the patients in a 'semi-confidential' atmosphere,

i.e. in one separate room with no other persons present, however not always with the possibility to close the door. However, there were little opportunities for other persons to overhear the interviews. Each interview, recorded and transcribed verbatim, was analysed before the next scheduled interview to identify important issues and ideas about links between emerging codes. Memos were written directly after each interview and during the analysis. In addition to the interviews, informal dialogues were conducted and reported in the field notes [133]. *The field observations* were direct (no time delay between occurrence and registration) and theory-building with a low level of structure for data gathering [123, 134], i.e. the observer collected as much information as possible concerning a broad research question without being restricted to a theory or static observation questions. The author visited the patients' homes frequently over a period of time and participated in small talk to become familiar with the informants, but did not become involved in care situations. Focus for the observations were care situations, patient-caregiver interactions and interactions between the caregivers (Attachment 1). The authenticity during the observations was judged against two criteria: 1) whether a situation would occur irrespective of the researcher's participation (researcher perspective), and 2) whether the interaction between individuals would exist irrespective of the participants' awareness of the observation (participant perspective) [135]. The first observations were open, but became more focused once theoretical categories and processes had been created. In addition to direct observation notes, field notes were written immediately after the observation.

4.2.7 Theoretical sampling procedure

Theoretical sampling was conducted continuously in accordance with GTM [122, 123], and the data collection was influenced by the on-going data analysis. The first sample (setting 1) was selected to ensure several encounters with a variety of caregivers. For subsequent sampling (settings 2-4), these were selected to ensure variation in the type of care arrangement relating to factors such as patients' age and care needs. The variation in data was optimised by visiting each patient on several occasions at different times of the day, which also enabled several caregivers to be observed. The questions and observations became more focused as the analysis progressed and concepts and categories emerged. In the final sample (setting 4), the general observation time was reduced in favour of more specific observations and questions, which were guided by the emerging theory.

4.2.8 Data analysis

Open, focused and *theoretical coding* were performed in order to develop a theoretical model that was well grounded in data. The patients' and caregivers' own words, together with data from the observed actions, were used as much as possible to capture the substance of data. Also, to assure variability in the data, quotes and notes from all settings and informants were used. In the *open coding*, transcripts were read line by line and incidences coded; 33 codes were identified, for example *hanging loose* and *one step ahead.* In the *focused coding*, categories were filled with new data; comparisons were made code-by-code and category-by-category. Similarities and differences were identified and finally codes were condensed into categories with subcategories. Two categories, *exposure* and *control*, were identified as important to both patients and caregivers, leading to new questions on strategies. How did the patients handle their exposed states? What did they do to gain control? The same questions

arose regarding the caregivers. In the ongoing research process it now became obvious that there were two processes emerging from data: One with the perspective of patients' experiences and actions, and one with the perspective of the caregivers, respectively. The two actors (patients and caregivers) used strategies to gain control but somewhat differently. Thorough continued focused coding and theoretical coding the categories were conceptualized and related to each other in each of the two evolving core processes. Theoretical saturation was determined when all categories were adequately filled and no additional categories had emerged, resulting in two theoretical models presented as study I and study II.

4.3 STUDY III AND STUDY IV

4.3.1 Research setting

The questionnaire study was performed in Stockholm County, Sweden, over a period of 12 months (2011-2012).

4.3.2 Participants

The participants consisted of caregivers (with the term HC assistants used in publications) employed in Stockholm County Sweden, working with adult patients (> age 18 with no upper limit), dependent on 24-hour home care and enrolled in a HMV clinic. The comparison data (study IV) was obtained from the Health Survey, a comprehensive public health survey repeated every four years on randomly selected individuals from the adult population (age 18-84 years) of Stockholm County, including a wide array of demographic, socio-economic health, and lifestyle factors [136, 137].

4.3.3 Data collection and procedure

After approval from heads of two university hospital clinics specialising in HMV, one in the south and one in the north of Stockholm County, a list with 43 patients were obtained with the help of clinic-based contact persons. The list contained telephone numbers to a contact person (a manager or the patient), which were used as a first contact. If the contact person gave permission, written information was sent to the workplace (i.e. patients' home or to a staffing office). Of the 43 contacted workplaces, 28 confirmed their participation, four did not answer the phone call, three did not respond back after the first contact, four patients did no longer need 24-hour home care, three patients declined participation and one patient had been admitted to the hospital. The number of possible respondents had to be estimated as the contact persons could not give a definite number of ordinary and temporary caregivers in each workplace. Ten workplaces chose to have the author on a staff meeting informing and distributing questionnaires and 18 chose mailed questionnaires. A total of 215 questionnaires and information letters were distributed to the workplaces during the data collection period. Two reminders were sent, one by e-mail after one month followed by a second via e-mail and additional questionnaires sent by mail after approximately two months. A total of 128 respondents (60 %) returned a completed questionnaire (Figure 1).

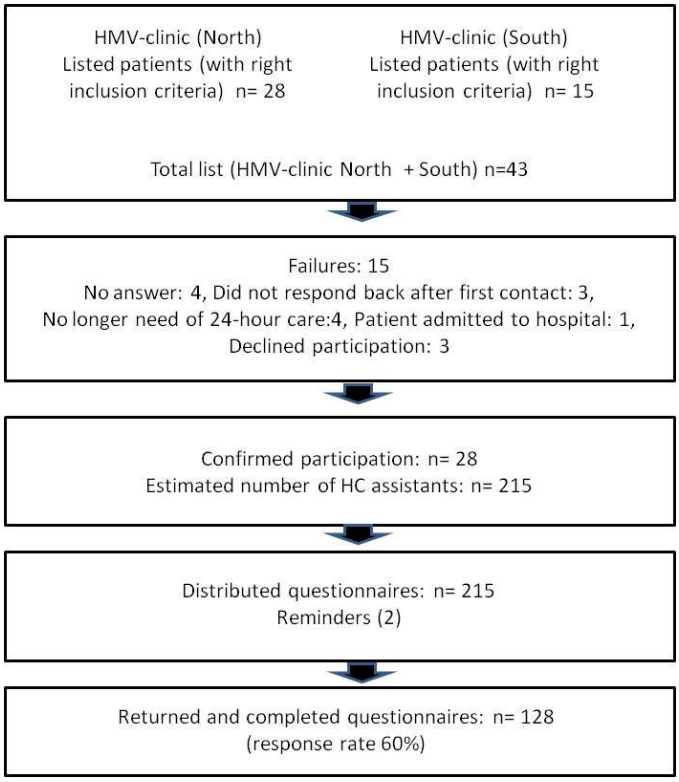

Figure 1. Data collection process.

4.3.4 Questionnaires

4.3.4.1 Study-specific questionnaire

To assess caregivers' perceived competence and responsibility (study III) and their perceived working conditions (study IV), a study-specific questionnaire, in Swedish, was constructed (appendix 2). Questions were derived from the qualitative results (Study I and II) and complemented with questions on working conditions in accordance with the Demand-Control model. Two caregivers with experience from home care and HMV care were asked to complete a pilot questionnaire and provide comments, followed by a review by two registered nurses who read the questionnaire carefully. Only small grammatical changes were performed.

4.3.4.2 Perceived competence

Perceived competence included four questions: 'I have the health care knowledge needed to work here', 'I have enough knowledge to handle the home ventilator in a safe manner', 'I have enough knowledge to handle other home care technology used here' and 'If the home ventilator breaks down, I do know how to act'. Internal consistency, calculated using Cronbach's alpha, was 0.71 for perceived competence

4.3.4.3 Perceived responsibility

Perceived responsibility included two questions: 'I think I take more responsibility for the patient than others do' and 'If needed I take the role as a coordinator here'. The respondents were asked to rate their answers on a four-point Likert scale, which ranged from 'totally

agree' to 'totally disagree'. Internal consistency, calculated using Cronbach's alpha, was 0.65 for perceived responsibility.

4.3.4.4 Perceived working conditions

Perceived working conditions were measured in terms of *psychological demand*, *control* (also described as decision authority), *stimulance* (also described as skill discretion) and *social support* according to Karasek and Theorell [91]. The Swedish shortened 11-item version of the Demand-Control Questionnaire [138, 139] of the Job Content Questionnaire [141] was used to measure perceived psychological demand, control and stimulance. Perceived social support was measured using two study-specific items. Perceived psychological demand included five questions, 'do you have to work very hard?', 'do you have to work very fast?', 'is the work load too big?', 'do you feel you have enough time for assigned duties?' and 'do you experience contradictions in your work?'. Perceived control included two questions, 'do you feel free to decide *what* to do in your work?' and 'do you feel free to decide *how* to do your work?'. Perceived stimulance included four questions, 'do you get opportunities to learn new skills at work?', 'does your work require skills?', 'does your work require inventiveness?' and 'does your work include repetitive tasks?'. Perceived social support included two questions, 'do you feel supported by your manager/colleagues?'. The respondents were asked to rate their answers on a four-point Likert scale, which ranged from 'almost never' to 'often' and a sum score was calculated for each respondent on each index. Internal consistency was calculated using Cronbach's alpha, 0.54 (psychological demand), 0.88 (control), 0.37 (stimulance), and 0.47 (social support).

In addition, four statements to describe the respondents' perceived *working environment* were included: 'The physical/psychosocial environment is good at my workplace', 'bullying and/or discrimination do exist at my workplace' and 'I have the intention to stay at my workplace for the next two years'. The respondents were asked to rate their statements on a four-point Likert scale (ranging from 'fully agree' to 'fully disagree'). The statements were dichotomized for statistical analysis.

4.3.4.5 Socio-demographic background

Socio-demographic background information was collected on sex, age, country of birth (Sweden-other), educational level (compulsory, secondary, university), formal healthcare training (yes-no, name and length) and work experience with home ventilator (<1 year, 1-5 years, >5 years). Age was stratified into <30, 30-50 and >50 years. Formal healthcare training was stratified into 1 month-2years and > 2 years.

4.3.4.6 Workplace background data

The participating caregivers' workplace data was collected on type of employment (municipality or private company), assigned workplace manager (yes-no), amount of time working alone (>50 or <50% of full-time work), 'on-the-job training', on home ventilator skills (yes-no) and clinical supervision (yes-no).

4.3.4.7 Patient characteristics

Information about patient characteristics was collected in order to understand the caregivers' working situation, including the patients' socio-demographic and caring need data (Table 3). Patients and respondents accepting the study were promised confidentiality, meaning that no answers should be traceable to any specific patient and his/her care team. Therefore, it is not possible to know how many respondents completed the questionnaire from each workplace, nor if there were respondents from all 28 workplaces who accepted participation in the study or not. Therefore, the obtained information about patient characteristics have not been used in any statistical analyses but only as an overview for deeper understanding of caregivers' working conditions. This was a necessary restriction in order to perform the study.

Table 3. Patient characteristics as described by the caregivers.

Variables	Sub variables	Characteristics	*n*	*%*
Socio-demographic background	Sex	Male	102	80
		Female	25	20
	Age (years)	<30	38	30
		30-50	4	33
		>50	84	67
	Living arrangement	Single	72	56
		with family	56	44
	Housing	House/apartment	112	88
		Group housing	16	12
HMV care needs	*Home mechanical ventilation*	Life –support (24 hours)	87	68
		Parts of day/night (<24 hours)	41	32
	Ventilator interface	Tracheotomy	112	88
		Facial/nasal mask	16	12
		Secretion clearance with use of suctioning	106	83
ADL	*Cognitive ability*	Normal	110	86
		Decreased	18	14
	Communication ability	Verbally	87	32
		Use of communication tools	41	68
	Nutrition	Able to eat normally (by self or with help)	62	48
		Nutrition via enteral feeding	66	52
	Physical functioning (mobility)	Normal	15	12
		Decreased	112	88
Homecare technology needs		Ventilator	128	100
		Cough assist	80	62
		Nutrition pump (enteral feeding)	60	47
		Electric bed	119	93
		Electric hoist	110	86
		Nebulisation devices (for inhalations)	37	29
Care contacts*		Primary care centre	101	86
		District nurse (home visits)	85	66
		Local general hospital	56	44
		HMV centre	96	75
		Specialist care (e.g. neurology, pulmonary)	40	31
Workgroup size (caregivers)		Ordinary caregivers [n=1-22, mean 6.25]		
		Temporary caregivers [n=1-24, mean 8.36]		

* Several respondents reported 'I don't know'

4.3.5 Data analysis

In study III, socio-demographic and workplace background variables were analysed and described as frequencies and percentages. *Perceived competence* and *perceived responsibility* sum scores showed skewed distributions and were therefore dichotomised at the 75th percentile, assigning a "1" to respondents giving higher scores, and a "0" to respondents giving lower scores.

Associations between independent variables (socio-demographic and workplace background) and perceived competence and perceived responsibility were calculated using Pearson's (χ^2) test with 95% confidence intervals. Significant associations were further analysed by estimating odds ratios (OR) with 95% confidence intervals (CI) using logistic regression models analysing the effects of socio-demographic and workplace background data (sex, age, educational level, formal healthcare training, on-the-job training and clinical supervision) on perceived competence and perceived responsibility [142]. Reduced models were calculated by selecting significant variables (p=<0.1 for perceived competence and p=<0.05 for perceived responsibility). The full models showed a goodness of fit of 0.41 and 0.46 for perceived competence and perceived responsibility, whereas the reduced models showed a goodness of fit of 0.58 and 0.82 for perceived competence and perceived responsibility, respectively.

In study IV Background variables (socio-demographic and workplace) and dichotomised responses, were described by frequencies and percentages and differences were analysed using the χ^2 -test. Working condition indices (*psychological demand*, *control*, *stimulance*, and *social support)* were presented as sum scores, and means and standard deviations were calculated, and differences were analysed using Student's *t*-tests. The four-graded statements on working environment were dichotomised to Agree (1, fully agree + 2, partly agree) and Disagree (3, partly disagree + 4, fully disagree). For comparison between the study group and the comparison group on working conditions, responses on the four-graded scale were dichotomized to Yes (1, always + 2, almost always) and No (3, almost never + 4, never). In the statistical analysis, all background variables were collapsed into two categories. Stata version 11.0 was used for all the analyses [143].

4.3.6 Comparison data (study IV)

The latest accessible data from the Health Survey conducted in 2010 [136] was obtained (*n*= 30767, response rate 55.6%). Data results are categorized after respondents' occupation according to the Swedish Standard Classification of Occupations [144], based on International Classification of Occupations. From the Health Survey [136], occupational code (5133) for caregivers within home, elderly and community care, i.e. general home care, was chosen for comparison (*n*=585). *The comparison data* consisted of 11 questions drawn from the extensive survey [136], six background variables (sex, age, country of birth, educational level) and seven questions, identical to the questions included in the four working condition indices used in the study questionnaire, all with four-graded answers: Two questions on demand, 'do you feel you have enough time for assigned duties?' and 'do you experience contradictions in your work?', two questions on control, 'do you feel free to decide *what* to do at work?' and 'do you feel free to decide *how* to do your work?', one question on stimulance; 'do you get opportunities to learn new skills at work?' and finally two questions on social support; 'do you feel supported by your manager if you experience problems at work?' and 'do you feel supported by your colleagues if you experience problems at work?'.

4.4 ETHICAL CONSIDERATIONS

All projects included in this thesis were approved by the regional Research and Ethics Committee at Karolinska Insititutet, Sweden. Registration numbers were 2007/170-31 (Study I and II), 2011/5:7 (Study III and IV) and 2010/1879-31/5 (the Stockholm Public Health cohort). For study I and II, information on the study was provided to all participants and written consent was obtained. Participant anonymity and confidentiality was guaranteed with special consideration taken to the patients enrolled in the study. Prior to sensitive care situations during observation, the patients were asked if ¨the author could have the permission to be present. Given the small sample size, confidentiality was maintained by not linking the quotes to specific informants and by using the pronoun 'she' when quoting, regardless of the sex of the patients or the caregivers. For study III and IV, a return of a completed questionnaire was considered to represent informed consent since the information letter stated voluntary and confidential participation.

5 MAIN RESULTS

In this section, the term HC assistant will be used to describe the caregiver.

5.1 STUDY I

The patients strived for control and safety in their homes through compensatory processes when their care was not suited to their needs. The core process was labelled *Grasping the lifeline*, describing patients actions of *taking control*, *seeking safe hands* and *navigating in the care system* (table x). The patients' main concern was how to manage their exposed states without 'losing the lifeline'. Losing the life-line meant being in *lack of control, in unsafe hands* and being *insecure in the care system.* When patients were holding on to the lifeline, their strivings showed the desired effect and they felt in control and safe. The substantive grounded theory is illustrated in the theoretical model shown in Table 4.

Table 4. Theoretical model *Grasping the lifeline***.**

Losing the Lifeline ⟷	**Grasping the Lifeline** ⟷	**Holding on to the Lifeline**
Lack of control	**Taking control**	**In control**
Being mastered by others	Striving to be one's own master	One's own master
Having HCA unsuited to needs	Selecting HCA	HCA suited to needs
In unsafe hands	**Seeking safe hands**	**In safe hands**
Feeling unsafe in care procedures	Instructing unskilled HCA	Safe in care procedures
Feeling unseen and unheard	Trying to be seen and heard	Seen and heard
Insecure in the care system	**Navigating in the care system**	**Secure in the care system**
Lack of interest	Making own contacts	Good contact
Lack of connection	Coordinating own care	Connection

5.1.1 Patients striving for control and safety

A summary of the extensive theoretical model is presented below with the compensatory processes as a point of departure, i.e., the patients' strivings for control and safety by taking control, seeking safe hands and navigating the care system.

5.1.1.1 Taking control

Patients *tried to take control* by *striving to be their own masters* and by *selecting their own HC assistants*. The HC assistant's attitude to the patient's right to decide was important in terms of feeling one's own master. The patients' dependency on their HC assistants made them want to take part in the selection process. 'I really want to participate in the selection of

HC assistants. Not everybody fits in here!' one patient said. Owing to a high turnover rate among HC assistants, the patients were faced constantly with new persons caring for them, which was a stressful experience. One of the patients had 17 HC assistants with new persons coming for introductory shifts several times a week due to a high turn-over rate.

5.1.1.2 Seeking safe hands

The patients *sought safe hands* by *instructing untrained HC assistants* in care procedures and by *trying to be seen and heard*. By instructing their HC assistants, the patient remained in control and felt safe in the care. The performance of care procedures by an experienced HC assistant with the skills to handle the medical and technical equipment correctly made the patient relax and gave the patient the feeling of being in safe hands, which was also observed.

The HC assistant puts her hand on the patient's chest in order to detect secretion in the airways. She then prepares the suction supplies and starts to remove the secretion from the tracheotomy. She is quiet and works efficiently (observation).

Communication with the HC assistants was central to the patients when trying to feel that they were seen and heard. Lack of communication skills in the HC assistant could create feelings of being unheard. When the HC assistant did not speak or understand Swedish (the patient's language),the patient felt unsafe. One patient, in despair when her HC assistants did not understand the instructions on what to do, said: 'If I tell them one thing and they do the total opposite, then something is wrong'. The observations also revealed other situations in which the patients appeared to be unseen and unheard. For example, care situations were performed without the HC assistants engaging with or listening to the patient.

The TV is turned on, at a very high volume. The HC assistant manipulates the feeding tube with one hand and watches the TV at the same time. She changes TV-channel with the remote control using the other hand and keeps on watching (observation).

5.1.1.3 Navigating the care system

When *navigating the care system*, the patients *made own contacts* with health care professionals and *coordinated their own care*. When necessary, a devoted HC assistant could take over the navigating role. According to the patients and their HC assistants, they felt a lack of interest from healthcare professionals who made few home visits and contacts were sparse. To compensate for this lack, the patients tried to *make their own contacts*. One patient was satisfied because she had established direct contact with the hospital instead of having to go through the primary care centre. The patients *coordinated their own care,* sometimes with help from their HC assistants, when they experienced a lack of collaboration within the care system. 'No, they do not speak with each other. They are on different planets, totally separated from each other', one patient described the lack of collaboration between her healthcare professionals, responsible for different parts of her care.

5.2 STUDY II

The core process identified was the HC assistants' strivings to combine safe home care with good working conditions by using compensatory processes, *day-by-day learning, balancing relations with the patient, self-managing* and *navigating the patient care system.* The HC

assistants' main concern was how to manage their working situation while experiencing barriers, identified in this study as *competence gap*, *trapped in the home setting*, *poor supervision* and *unconnected to the patient care system* (Table 5).

An additional and important finding was the identification of an inclusive approach among the HC assistants, describing their compensation for their own barriers as well as those of their colleagues'. The HC assistants then took responsibility for the overall situation at the workplace by taking the learning needs of the colleagues into account, by balancing the relationship between the patient and workgroup and by taking on the role as an informal leader as well as a patient navigator. In contrast, signs of non-inclusive approaches among HC assistants not taking overall responsibility for the workplace were also identified. These HC assistants did not contribute to collegial learning but instead developed the role of a solo expert, with the attitude that things were not working if they weren't present, and by accepting the role as a patient favourite with the risks of imbalance within the workgroup.

Table 5. Identified barriers and compensatory processes.

Identified barriers	Compensatory processes
Competence gap	**Day-by-day learning**
Lack of training	On-the-job-practice
No prior experience	Self-learning
Difficulties with learning in the workplace	Collegial learning
Trapped in the home setting	**Balancing relations with the patient**
Poor working environment	Staying sufficiently distant
Mastered by patient	Staying sufficiently close
Poor supervision	**Self-managing**
Lack of formal leadership	Forming informal leadership
Unclear routines	Peer-support
Unconnected to the patient care system	**Navigating the patient care system**
Lack of coordination of patient care	Coordinating patient care
Left alone	Acting one step ahead

5.2.1 HC assistants' strivings to combine safe home care with good working conditions

A summary of the theoretical model will be presented with focus on the four compensatory processes day-by-day learning, balancing relations with the patient, self-managing and navigating the patient care system.

5.2.1.1 Day-by-day learning

HC assistants compensated for their gaps in competence by seeking learning situations themselves through *on-the-job practice*. *Self-learning* was the major way to learn the routines and get used to the home care technology, and the HC assistants took own responsibility in

finding learning situations. Self-learning could also be achieved by trouble-shooting, when the HC assistants experienced problems with the home care technology. One HC assistant described how she handled a stressful situation with a beeping and alarming home ventilator on a bus trip with the knowledge that a leakage in the system would be potentially dangerous to the patient. *Collegial learning* was another method used by the HC assistants to compensate for colleagues' gaps in competence as all HC assistants needed to trust each other if something unexpected happened. One junior HC assistant was observed following her senior colleague closely, letting the senior colleague decide both the order and pace of care for the patient. In addition to teaching practical skills, the experienced HC assistants inspired new colleagues to adopt good work ethics and proper behaviour. In some cases the experienced HC assistants even felt the need to check on and even correct improper behaviour among the junior colleagues.

5.2.1.2 Balancing relations with patient

The barrier 'trapped in the home setting' illustrated the special working conditions these HC assistants experienced when delivering advanced care in the home of the patient. Some HC assistants felt controlled by the patient in everything they did. 'She controls our time and can ask us if we're on vacation if we take just a short break'', one HC assistant said. There was little that the HC assistants could do about a poor working environment, except alerting their managers. However, they could compensate for mastering patients by maintaining an appropriate balance in their relationship with the patient by acting professional without becoming too distant, *staying sufficiently distant*, thus finding a balance between the patients' right to decide and her actual care needs. HC assistants were sometimes advised by their managers to support each other and sometimes set limits towards a patient. *Staying sufficiently close meant*, on the other hand that the HC assistant had a close relationship with the patient but without becoming too personal. There was however always a risk for the relationship to become too personal, and patients often had favourites among the experienced HC assistants, who were then willing to make personal sacrifices, such as working extra hours and on special occasions at the patients' request. HC assistants, who were not chosen, could feel less worthy compared to the favourites. One HC assistant described an occasion when her patient planned a vacation trip with her 'favourites', leaving her and a colleague out. 'We were not asked if we wanted to come too. It felt hard not to be chosen'.

5.2.1.3 Self-managing

Absent managers and unclear routines resulted in poor supervision, experienced as a barrier to safe care and good working conditions. 'This workplace feels like a playground', one HC assistant said when describing her colleagues' ignorance about existing routines. *Forming informal leadership* was one way to compensate for the lack of formal leadership. The HC assistants took over some of the managerial role, such as maintaining contact with authorities and managing the staff schedule. *Peer-support* was another compensation, which enabled the workgroup to support one another, particularly in the event of threat. For example, when questioned by the manager about the need for two HC assistants on a 24-hour basis, the workgroup protested because of the patients' substantial care needs requiring life-support technology.

5.2.1.4 Navigating the patient care system

Being responsible for the safety of the patients, the HC assistants often felt they had to step in and *coordinate patients' care* because of a lack of collaboration between the healthcare professionals. 'As soon as she needs medical care we have to call several persons. They can't even call or send an e- mail to each other', one HC assistant said. The lack of connection became particularly important when a patient was in need of acute care. The HC assistants did not always know who to contact or experienced lack of interest when they contacted the HC professionals they thought were appropriate. During evenings and nights, when the regular primary care centre was closed, the HC assistants found it even more difficult to get the required assistance. Difficulties in obtaining help from the national emergency number (112) were described as very stressful. When one patient needed acute care the HC assistants were startled when they called 112 to expect assistance from paramedics and ambulance, but instead were told they had to wait because of a need of a special ambulance due to the patients' home ventilator. By *acting one step ahead* the HC assistants prepared themselves for emergencies, for example, by creating telephone lists and checking the first aid kit regularly. A patient leaving the home with a life-support ventilator required an alert HC assistant: 'I must have my eyes and ears alert all the time because bad things can happen to the patient anytime and anywhere, even on the bus!'

5.2.2 Patients' and HC assistants' connections to the care system

To summarise, three descriptions on how patients (study I) and their HC assistants (study II) experienced the care system are shown in Figure 2: (A) Insecure in the care system, illustrated by an absence of connections between the patient/HC assistant and the professional care providers; (B) Navigating the care system, illustrated by the compensatory process when the patient/HC assistant maintained their contacts with the professional care providers and coordinated the care themselves; (C) Secure in the care system, illustrated by existing connections between all actors involved.

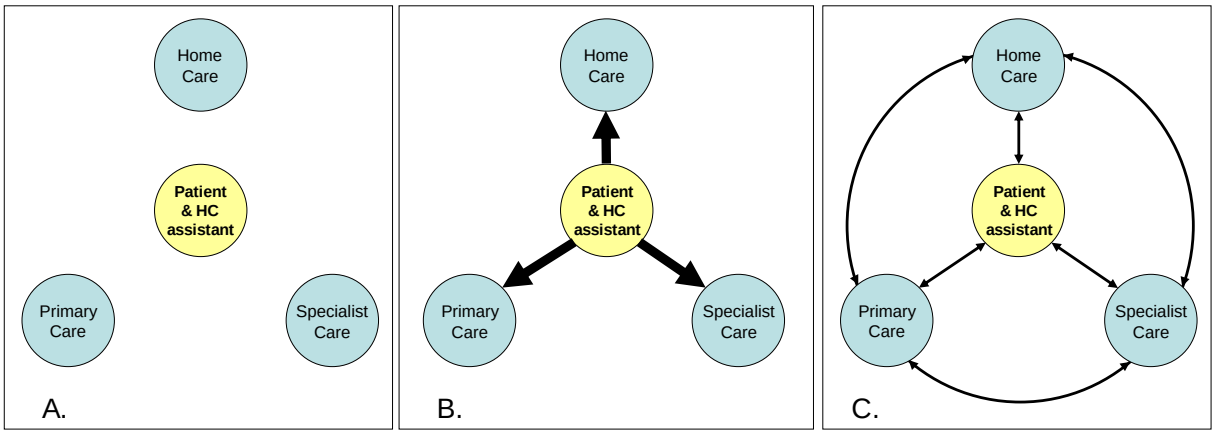

Figure 2. Patients' and HC assistants' connections to the care system.

5.3 STUDY I AND II IN RELATION TO STUDY III AND IV

Findings from study I and II highlighted the importance of the caregivers' compensatory processes in delivering 24-hour home care to patients with substantial care needs. The studied caregivers performed advanced care and took a large responsibility in the care of the patient,

and were found compensating for experienced barriers regarding their competence gap, their relation to the patient and to colleagues and their lack of support, making their working situation challenging. Particularly the inclusive approach among some caregivers, who were found to take overall responsibility for the workplace, seemed to be a key factor explaining how advanced care could be performed without formal training. This finding suggested the need of further investigation on a larger data set. For further quantitative studies, an appropriate group of caregivers' in 24-hour HMV care was therefore chosen with the aims to investigate their socio-demographic and workplace background as well as their perceptions on competence, responsibility and working conditions.

5.4 STUDY III AND STUDY IV

The socio-demographic and workplace background of the HC assistants (n=128), working with patients in need of 24-hour home care due to HMV and other advanced caring needs, were investigated.

5.4.1 HC assistants socio-demographic and workplace background data

Female HC assistants made up 72% of the respondents with ages evenly distributed. Forty-one per cent were not born in Sweden. Sixty-six percent had at least completed secondary school, 55% (n=70) lacked formal health care training exceeding 30 days, 27% (n=34) reported shorter courses, and 19% (n=24) had training equivalent with a licensed practical nurse exam (LPN). Employment was evenly divided between local municipalities and private agencies and 20% had less than 1 year of experience with HMV care. Forty-one percent of the HC assistants reported having an assigned workplace manager, and 33% reported working alone more than 50% of their time. On-the-job training on home ventilator handling and maintenance was received by 84% 'at least one time'. Forty-five per cent reported clinical supervision on a regular basis at their workplace (Table 6).

Table 6. HC assistants socio-demographic and workplace background data (n=128) and comparison (χ^2) between males and females.

Variables	Sub variables	Characteristics	Total *n* (%)	Male *n*	Female *n*
Socio-demographic background	Sex	Male	36 (28.1)	-	-
		Female	92 (71.9)	-	-
	Age (years)	<30	43 (33.6)	17	26
		30-50	47 (36.7)	11	36
		>50	38 (29.7)	8	30
	Country of birth	Sweden	75 (58.6)	22	53
		Other	53 (41.4)	14	39
	Educational level	Compulsory	15 (11.9)	2	13
		Secondary	83 (65.9)	25	58
		University	28 (22.2)	9	19
	Formal healthcare training (if yes: duration)	Yes	58 (45.3)	9*	49*
		1 month-2 years	*34*	*6*	*28*
		> 2 years	*24*	*3*	*21*
		No	70 (54.7)	27*	43*
	Work experience (with HMV)	<1 year	25 (19.7)	9	16
		1-5 years	67 (52.8)	17	50
		>5 years	35 (27.5)	10	25
Workplace background	Employment	Municipality	65 (51.6)	11*	25*
		Private company	61 (48.4)	25*	36*
	Assigned workplace manager	Yes	52 (40.6)	13	39
		No	76 (59.4)	23	53
	Working alone	>50%	43 (33.6)	14	29
		<50%	85 (66.4)	22	63
	On-the job-training (HMV skills)	Yes	108 (84.4)	29	79
		No	20 (15.6)	7	13
	Clinical supervision	Yes	57 (45.2)	15	42
		No	69 (54.8)	21	48

* p-value <0.01

5.5 STUDY III

Despite limited formal training (55% lacked formal healthcare training), a majority of the 128 HC assistants (80%) rated their *perceived competen*ce as high and 59% rated their *perceived responsibility* as high. Males lacked formal healthcare training to a greater extent than females and rated their competence accordingly.

5.5.1 Factors associated with perceived competence

Female HC assistants rated their perceived competence 2.4 times higher (OR=2.4; CI=1.0-6.2) than the males. The HC assistants who reported on-the-job training at their workplace rated their perceived competence three times higher (OR=2.9; CI=1.0-8.5) than the ones with no such reported training.

5.5.2 Factors associated with perceived responsibility

Younger HC assistants rated their perceived responsibility three to four times lower compared to their older colleagues (OR=4.1; CI=1.5-11.2 for age 30-50 and OR=3.1; CI=1.0-9.0 for age >50). The HC assistants who reported on-the-job training rated their perceived responsibility 13 times higher (OR=12.8; CI=2.4-68.3) and respondents who reported clinical supervision rated three times higher (OR= 3.0; CI=1.3-7.0) than the ones with no such reported activities.

5.6 STUDY IV

The aim of this study was both to analyse the 128 HC assistants' perceived working condition in terms of perceived psychological demand, control, stimulance, social support and working condition, and to compare them with a larger group of HC assistants working in general home care (n= 585).

5.6.1 Relations to the comparison group

The studied HC assistants (n=128) working in HMV care were compared to HC assistants working in general homecare (n=585) regarding their background factors and perceived working conditions. Significantly more males and a higher educational level were found among the HC assistants in HMV care, who also rated lower on psychological demand than the comparison group. No other significant differences, but tendencies, were identified between the two groups.

5.6.2 Factors associated with perceived working conditions

High ratings on psychological demand were associated with country of birth (respondents not born in Sweden rated higher) and reported clinical supervision at the workplace, high ratings on control were associated with age (> 30 years rated higher) and reported on-the-job training at the workplace, and high ratings on stimulance were associated with sex (females rated higher) and reported formal healthcare training. No significant associations were found for social support.

5.6.3 The working environment in HMV care

One in five of the HC assistants reported poor physical work environment, one in five poor psychosocial work environment, and 29% reported that bullying and/or discrimination existed at their workplace. A majority (76%) reported an intention to stay at the present workplace for the next two years. Reported bullying and/or discrimination at the workplace was more commonly reported by municipality employed HC assistants versus privately employed HC assistants (p=0.05), by HC assistants having no assigned workplace manager (p=0.002) and by HC assistants who reported clinical supervision at the workplace (p=0.01).

6 DISCUSSION

The results from the four studies are discussed in terms of their combined contribution to new and broadened understanding of home care for patients in need of advanced care and technology.

6.1 HOW PATIENTS AND CAREGIVERS MANAGE 24-HOUR HOME CARE

The studied patients had chosen to stay home despite their substantial care needs and the initial research question was how they and their caregivers experienced and managed receiving and delivering advanced care in the home, far away from professional competence and support normally found in hospital settings.

6.1.1 Advanced care 'moves home'

Home care is becoming more advanced, blurring the boundaries between hospital care and home care. These studies' findings indicated patients' strong wishes to remain at home, despite large needs of advanced care and technology requiring caregivers around the clock, as also emphasised by others [47]. Öhlén et al [145] conducted a review directed at concept clarification on 'at-home-ness' despite illness and disease and found three interrelated aspects of being safe, being connected and being centred. Patients with impaired breathing and in need of prolonged mechanical ventilation are commonly cared for in intensive care units or specialised clinics due to their complex needs, as regular wards hesitate because of lack of staff competence. In contrast, when the patient is moving home to receive HMV care, no formal healthcare training is required for the caregivers' employed for the 24-hour responsibility of the patient [60, 20]. The results from the questionnaire study showed a relatively low level of formal healthcare training among the studied caregivers working in HMV care. Of the 128 respondents, only 45% reported any healthcare training above 30 days, and one in five held a diploma equivalent with an LPN-exam. Lack of formal competence within home care is a known concern for the authorities [56] and patients' exposures due to lack of caregiver competence has been described earlier [35, 146]. Considering the advanced level of care often accompanied with HMV care, it was interesting to find out that as many as 80 % of the caregivers perceived their competence as high (study III). In summary, these caregivers with limited training worked in the home settings with patients in need of advanced care and technology, patients normally cared for by highly specialised nurses in settings with professional support close by. Despite the above known lack of formal competence among the caregivers as well as the identified difficulties experienced by patients and the caregivers (studies I-II), the patients wished to remain home and the caregivers felt competent and intended to stay at their present workplace the next two years (study IV). Four possible explanations as to how patients and caregivers managed 24-hour home care were found, grounded in this thesis' findings, and will be discussed.

6.1.2 Compensatory processes for safe care and good working conditions

One possible explanation as to how patients and caregivers managed 24-hour home care was the identification of compensatory processes, or strategies used by the patients as well as the caregivers (study I-II) in their strivings to overcome experienced difficulties. A summary of the compensatory processes for patients and caregivers are discussed below.

6.1.2.1 Patient strategies for control and safety

Patients in 24-hour home care were found compensating for experienced difficulties *by taking control, seeking safe hands* and *by navigating the care system* in their strivings for control and safety (study I). Patients' strategies were all related to their wishes to make own decisions and to participate, also described by Dreyer et al. [54] who found decision-making to be the most important factor for patients experiencing life-changing situations while in HMV care. The identified compensatory processes might be similar to descriptions in the literature of coping [147]. However, the found strategies in this study were mainly actions taken as a result of external difficulties, whereas coping commonly is defined as a reaction and effort to manage internal stressors [148]. The patients compensated for caregivers who were not suited to their needs by trying to select certain caregivers for specific situations and by controlling their work schedules to obtain certain competency when needed. By choosing caregivers they trusted and relied on, they felt in control and in safe hands. The importance of competent caregivers to trust and rely on in home care is very well supported in the literature on patients' and families' experiences [36, 35, 47, 51, 54].

6.1.2.2 Caregiver strategies to combine safe care with good working conditions

The caregivers working in 24-hour home care were experiencing several barriers affecting both the patients and themselves. With limited training and with a large responsibility, they were found striving to combine safe home care with good working conditions by the compensatory processes *day-by-day learning, balancing relations with the patient, self-managing,* and *navigating the patient care system* (study II). The caregivers' situations were strongly influenced by their workplace, the patients' homes, and the lack of normal structures commonly found in public work places, e.g. the presence of a manager. The work groups, varied in size between 8 and 17 caregivers with an addition of several newly employed and temporary caregivers with staff scheduling taking 24-hour home care needs requiring single or double-staffing into account. These factors contributed to several constellations of collaborations within the work group. The studied caregivers often felt left alone to manage difficulties commonly connected to structures, roles, and processes of work groups [77, 149] and seemed to compensate a lack of managerial support by employing self-managing. In the absence of a formal leader, informal leadership may develop if someone takes on the role and shows both psychological abilities to handle social interactions and required knowledge and skills to contribute in a given situation [78, 79]. The caregivers were also found to compensate by peer support when working together to take control of their situation by strengthening their group and by setting limits toward the patient, managers and HC professionals, well in line with definitions on peer support within the health care context [150]. The self-managing activities may be understood using theoretical perspectives on employeeship, as outlined by Bertlett [78], including co-operative relations between all employees, both leaders and followers. Compensating for a lack of managerial support, a climate of peer-employee style among the caregivers in contrast to a leader-follower style [78] was fostered.

6.1.3 On-the-job training makes the difference

As many as 80% of the caregivers in HMV care rated their perceived competence as high, despite their limited formal health care training in relation to their advanced work. A possible

explanation as to how patients and caregivers managed 24-hour home care is the identification of *on-the-job training* as an important factor for management strategies (studies I-II) and positive outcomes (studies III-IV). The patients instructed their unskilled caregivers in their strivings for safety (study I). This process could be understood as patients striving to maintain autonomy by the use of self-care, also described by Fex et al. in a study on patients' own handling of home care technology [31], but it could also be a sign of striving for safe care when patients felt unsafe with unskilled caregivers. The phenomenon of patients' in HMV care instructing their caregivers have been described previously [47, 35]. Problems that occurred as a result of communication difficulties made the patient feel unsafe in the hands of the HC assistant because they could not use the compensatory process of instruction.

When the caregivers lacked in competence, they took responsibility for self-learning by using previous experience and by finding self-learning situations themselves (study II). The caregivers' individual drive for self-learning was particularly observed when training needs were associated with home care technology, also described by Brooks et al. [53]. Collegial learning was yet another identified strategy frequently used when experienced caregivers introduced new colleagues to the workplace. Collegial learning is similar to peer teaching and peer learning, commonly used in clinical education within nursing programs [151]. The learning situations, both self- and collegial learning, took place in the workplace, i.e. in the home setting in front of the patient and in parallel with the daily care, well in line with Lave and Wengers' [108] description of situated learning as learning taking place in the same function, context and culture in which it occurs (i.e., it is situated) and with social interactions and collaboration as essential components. The importance of the workplace is also in line with the concept of work-based learning, outlined by Manley et al. [103], making the learning process not only enhancing on an individual level, but also enhancing team and organisational working practices. The qualitative findings pointing towards positive effects of on-the-job training are well supported by the quantitative results in study III and IV. On-the-job training on home ventilator skills 'at least once' was reported by 84% of the respondents and was significantly associated with high ratings of perceived competence and perceived responsibility (study III). On-the-job training was also associated with high perceived control, thus having an impact on caregivers' perceived working conditions (study IV).The practical skill-training strategies observed in all studies in this thesis correspond to well-established concepts of Schön's' [106] 'reflection-in-action', sometimes described as 'thinking on our feet', understood as the use of own experiences and feelings in building new understandings of the situation that is unfolding.

6.1.4 'One-patient-care' essential for success

The results of these studies suggest that the availability of designated caregivers, i.e. caregivers scheduled to work solely in the home of the patient thus forming a workgroup, to meet the 24-hour care needs of these patients is a contributing factor as to how well patients and caregivers managed. The patients' felt safe with the continuity of being cared for by experienced caregivers but unsafe with unknown temporary staff (study I) and the caregivers strived to 'get to know the patient' and learn his/her special needs (study II). These findings are supported by the results on caregivers' perceived psychological demand (study IV) as well as their perceived competence (III). In the care of patients with HMV, the caregivers worked with one patient at the time, enabling them to have enough time to do their job.

Moreover, two thirds of the respondents also reported working with a colleague in a 'double-staffing' system. The caregivers perceived their psychological demand lower in comparison with similar groups [136, 139], a finding contrary to most other studies on healthcare workers, indicating higher demands on this group than on the general population [89]. This finding is in clear contrast to most other healthcare settings, including home care, where one staff-member usually cares for several patients, thus making them more at risk of high work-load and stress [97]. As comparison, patients in general home care studied by Gjevjon et al.[152] received 51 visits by 17 different caregivers during a four-week period. The caregivers' high ratings on their own perceived competence may indicate a positive effect of 'one-patient-care'. By working with one patient in the patient's home, the caregivers could learn the individual needs of the patient without being interrupted by other tasks, thus enhancing their perception of competence. This possible effect is supported by a study of Suhonen et al. [76] showing that individualised care was perceived higher among caregivers in home care settings compared to caregivers working in nursing homes.

6.1.5 The 'including caregiver' takes the lead

The results from the studies indicated the importance of the individual caregiver, yet another explanation as to how the 24-hour home care was managed. The patients, in study I, were found to rely heavily on their competent caregivers. The importance of the caregivers was accentuated by the results in study II, where the findings pointed to factors describing caregivers with an 'inclusive approach', describing their compensation for their own barriers as well as those of their colleagues'. 'Including caregivers' facilitated collegial learning, balanced the relations with the patient, took responsibility for the workgroup by self-managing and navigated the patient care system, thereby took responsibility for the workplace overall. In their search for the 'outstanding home care worker', Grosch et al [153] tested an instrument to measure person centeredness, indicating the caregivers' ability to relate to their patients, well in line with the findings in this study where the 'including caregiver' engaged in the needs of the colleagues as well, thus related to others then herself/himself only. The study (II) data indicated that work experience was an important factor among the 'including caregivers', a factor also described by Devlin and McIlfatrick [83] and Herber and Johnston [73], who both suggested the use of experienced home care workers as mentors for untrained colleagues in palliative home care. These indications were partly supported by the quantitative studies where older caregivers rated higher on perceived responsibility (study III) as well as on perceived control (study IV) both of which could indicate that age contributed to the development of 'including caregivers'. However, prior experience with HMV, expected to enhance the including approach was not associated with higher perceived competence, responsibility or control (study III-IV).

6.2 BALANCING THE ROCKS - CHALLENGES FOR SAFE 24-HOUR HOME CARE AND GOOD WORKING CONDITIONS

Patients and their caregivers strived to manage 24-hour home care much by themselves, and in the 'good examples', both patients and caregivers seemed in balance and in control. However, they compensated for difficulties which also involved organisational issues which they had little impact on. In a broader perspective, leaving patients and caregivers to manage their challenges by themselves without organisational support and control, could have

negative effects on perceived care and work situations as well as the quality of care. Supported by the findings of this thesis, a set of challenges in need of organisational attention for a safe 24-hour home care and good working conditions are discussed (Figure 3).

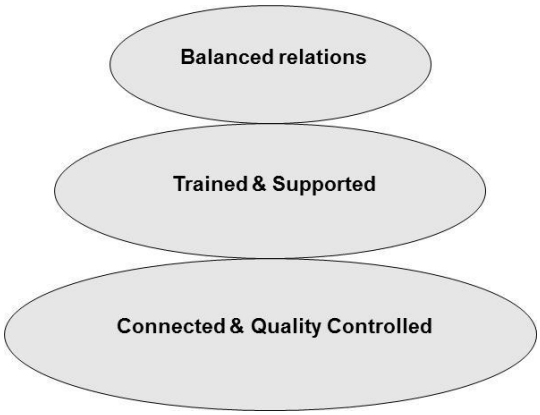

Figure 3: Balancing the rocks – challenges for safe 24-hour home care and good working conditions.

6.2.1 Balanced relations

When advanced care 'moves home' several boundaries are at risk of being blurred, leading to psychosocial challenges for the patients as well as the caregivers. Supported by the study findings, one proposal is that balanced relations could be an enhancing factor for safe home care and good working conditions. Patients took control by selecting caregivers and sometimes held favourites, which could lead to conflicts in the workgroup. The caregivers, on the other hand, balanced between 'private and professional' patient relation while struggling with collegial relations, often in the absence of managerial support (studies I and II). The patients, on the other hand, felt unheard when cared for by caregivers lacking in communication skills and unseen when cared for without empathy. The workgroup of caregivers also suffered from imbalanced relations when absent managers and lack of routines resulted in conflicts and, as one caregiver stated, made her workplace become a 'playground'. The caregivers described occasions when the patient's care needs collided with the patient's wishes, describing the caregivers 'intermediate positions' while doing public work in a private home, outlined by Mahmood and Martin-Matthews [74]. For the caregivers, this became a balancing act between acting professional without becoming too distant and being close without becoming too personal in relation to the patient. This finding is similar to Sims-Gloud and Martin-Matthews [154] description on building rapport, close connection, to the patient as one strategy used by caregivers for the purpose of providing personalised care, for patient approval as well as for their own work satisfaction. The struggle to meet the expectations from managers, HC professionals as well as the wishes and needs of the patient is also outlined by others [75]. Holmberg et al. [155] described patients' in home care balancing between own privacy and dignity, which empowered them in their relations with the professional caregivers.

6.2.2 Trained and supported

Lack of training and support were major reasons to why patients and caregivers felt the need to compensate in order to feel safe. Supported by all four studies, the need for training and

support is a comprehensive challenge to consider for safe home care and good working conditions.

6.2.2.1 Training – formal and informal

The caregivers' formal healthcare training was found relatively low, considering the level of care they performed and the results indicated that the workplace activity *on-the-job training* was significantly associated with high ratings on perceived competence, responsibility and control. However, workplace training may also involve training from co-workers (in study II, described as collegial learning) who themselves may have insufficient training. This may cause inappropriate training, thereby perpetuating poor care practice [83]. The risk of having caregivers with a low level of theoretical knowledge instructing others may be hazardous and the need for a minimum level of formal healthcare training is therefore important to ensure. Explanations for the caregivers' perceived high competence in study III (80 %), despite lack of formal training could have several causes. Firstly, the caregivers might not be fully aware of their own lack in knowledge [156], in line with Kuhn [157] proposing that the more we know, the more we realize that we are lacking in knowledge. Secondly, the currently used formal healthcare training in Sweden might not prepare the caregivers for their work to a sufficient degree, thus not affecting their perception of competence. Although some had home care-specific courses, most had completed courses dedicated mainly to hospital and nursing care, programs not preparing caregivers for advanced home care, a discrepancy described by others as well [158]. Thirdly, 'one-patient care' might also enhance caregivers' competence by the use of individualised care, also described by Suhonen [76]. As a contrast, perceived stimulance, a job resource that may balance negative effects of high demand and low control, thus minimizing job strain [98], was found significantly higher among caregivers with formal healthcare training, thus supporting the importance of formalised education (study IV). Perceived stimulance may be triggered by the skills needed in HMV care, including various skills within basic and advanced care combined with highly advanced technology. Female caregivers, more formal healthcare trained than the male caregivers, also felt more competent and stimulated than the male caregivers. To have appropriate training programs, ideally a combination of formal healthcare training and standardised workplace training is therefore of outmost importance and several studies have emphasised training needs to employed and family caregivers caring for patients with HMV and other advanced care needs [53, 159]. Lopez et al. [69] found a positive impact of a workplace training program on caregivers' job satisfaction, and White and Cadiz [68] described significant effects on an individual as well as an organisational level after workplace training of caregivers. On the contrary, patients with HMV, studied by Brooks et al. [53], have shown ambivalence to formal healthcare trained caregivers, as they feel 'hospitalized' with too much focus on nursing and healthcare instead of active life and well-being.

6.2.2.2 Different support for different needs

The findings on support were multi-facetted and in need to be discussed. Perceived social support was rated high, suggesting that the caregivers felt supported by their managers and colleagues (study IV). However this result must be contrasted to other contradictory findings. In the qualitative results, the caregivers seemed to compensate a lack of *managerial support* by employing self-managing, by employing informal leadership and peer support (study II).

Yet another indication could be found in the quantitative results on bullying and/or discrimination, reported less among caregivers with assigned workplace managers at their workplaces (study IV). When employing self-managing, the group could benefit from an informal leader using an including approach, i.e. a caregiver taking an overall responsibility for the workplace, or by peer support. However, workgroups without any 'outside control' might develop unhealthy forms of informal leaderships which may affect the psychosocial environment [77]. This is supported by the 'non-including approach' found in study II, i.e. when the caregiver did not contribute to collegial learning but instead took the role of the 'solo expert', and by accepting to become a patient favourite also excluded other caregivers from the 'inner circle'. Bullying and/or discrimination were reported by 29% of the caregivers which could be a signal of unhealthy leadership and group behaviour and need to be studied further. Workplace bullying in the healthcare sector has been widely studied [160] and the home care environment may put the caregivers at an increased risk of bullying and/or discrimination from colleagues as well as patient and family, although the present study did not address this issue in-depth, nor the patient- or family-related perspective.

Clinical supervision, reported by half of the caregivers in HMV care, increased the caregivers' perceived responsibility (study III) and psychological demand (study IV), a result contrary to commonly held theories on supervision as a supportive factor on work stress [116, 117]. This finding is somewhat difficult to interpret due to the lack of a definition of supervision in the questionnaire that may have caused respondents to focus on different aspects of the concept, such as training supervision, managerial supervision or facilitating (consultancy) supervision [161]. However, merely the fact that regular clinical supervision existed could be a sign of a well-managed workplace, with increased possibilities for the caregivers' to strengthen their roles, thus making them more confident in taking on responsibility for the patient and the workplace [83, 119]. Clinical supervision might also increase the participants' awareness of expectations from the patient, family and health care professionals and may have increased the caregivers' perceived psychological demand, consistent with Skovholt and Ronnestad [162].

Clinical supervision did not, contrary to expectation, increase the caregivers' perception of competence, control or stimulance (study III-IV).This might reflect that the caregivers prefer 'reflection-in-action' rather than 'reflection on action' ŧ106]. The practical on-the-job training, at the workplace is by nature characterized by 'reflection- in-action'. Supervision is instead 'reflecting-on-action', which means talking things through with a manager, colleagues or a counsellor, to explore the reasons behind the actions and the dynamics in the group [106]. These caregivers, working autonomously, might find clinical supervision not suited to their needs, or they might oppose to receive professional views from a counsellor or regard it as control from the management.

6.2.3 Connected and quality controlled

6.2.3.1 Connected to the care system

Staying connected to the care system is crucial to good care and lack of continuity in the chain of care is a risk factor. A patient in HMV care commonly has contacts with a local primary health care centre, a hospital-based HMV clinic and various specialist clinics

depending on diagnosis and care needs (study III-IV). Study I showed that the patients, when experiencing poor continuity in their care, felt they needed to navigate the system by themselves or with the help from a competent caregiver. This finding was accentuated in study II where the caregivers were found to take large responsibility in coordinating the care when HC professionals showed little interest in the patient or failed to collaborate, described as ‘ being on different planets’. The importance of good collaboration and continuity for successful home care [82, 164] and the lack of collaboration in the support of patients in Swedish home care, especially in case of advanced and multiple care needs, is already known, however with large regional differences [14]. Norwegian HC professionals in HMV care studied by Dybwik [115] described their frustration over lack of collaboration in the terms of ‘being between a rock and a hard place’.

The caregivers experienced a lack of support from HC professionals when their patient got seriously ill or in the case of an emergency, making them compensate by being prepared ‘one step ahead’ (study I and II). The degree of stress could be extremely high when no help was received even when they called the emergency number 112, supporting earlier findings on caregiver stress in advanced home care [163]. To secure patient safety and reduce caregiver stress, access to 24-hour support from HC professionals competent in advanced care and technology is needed.

6.2.3.2 Quality control needed for patient care and working conditions

Caregivers in Sweden take 24-hour responsibility for the care and safety of patients in need of advanced care and technology. Although organisational or quality of care perspectives were not primary objectives of these studies, findings reveal concerns regarding caregivers’ job situation which may pose risks to patient and caregiver safety, suggesting the need for quality control measures to be considered.

Firstly, the level of responsibility taken by the caregivers needs to be considered. Despite caregivers limited formal healthcare training, several advanced care and technology tasks were delegated to them by nurses in HMV clinics and primary care, thereby transferring responsibility for the patient, perhaps beyond caregivers’ capacity. Delegation to caregivers has been described as problematic by district nurses because of their limited time for providing training and for evaluation of the caregivers’ competence, which might significantly impact on patient safety and quality of care [27]. Thus the consequences of delegation when transferring responsibility from authorised HC professionals (nurses, physicians) to paraprofessionals call for extensive quality control on issues important for patient safety and caregivers competence in 24-hour home care. Secondly, the caregivers’ ‘intermediate position’, when doing public work in a private home [74], calls for special attention as their working environment may not be optimal. The reports of existing bullying and/or discriminations (29 %) by caregivers in HMV care is alarming and need further investigation. Also, the balancing relations with the patient, and family, might also be challenging for the individual caregiver. The responsibility for the caregivers’ physical and psychosocial working environment lies with the employer, often a local municipality or a private agency [86, 87].

6.2.4 Caregivers job situation and future needs

HMV caregivers reported no clear signs of high job strain, indicating that job resources, consistent with Bakker and Demerouti [98], act to balance any negative effects. A large majority of the caregivers had no plans to leave their jobs for the next two years. The predicted increase in number of patients with substantial care needs requiring home care will increase the demand for competent caregivers. The importance of preventing a future shortage of caregivers in the health care sector by focusing on job resources such as training and support for increased job satisfaction has been emphasised previously [99, 164, 67].The findings of 'including caregivers' with abilities to take overall responsibility for the workplace underscores the importance of ensuring that experienced and competent caregivers who are well suited for their work are provided with working conditions and incentives that encourage them stay in their position. These results can contribute to continued development of the caregiver role in HMV and other advanced care.

6.3 METHODOLOGICAL CONSIDERATIONS

A special feature of this thesis is the use of mixed methods in study design as well as the use of several data sources in the field study, actions which both broadened the understanding of conditions of home care for patients in need of advanced care and technology. With the use of an initial qualitative approach, findings from study I and II were used as a standpoint for the construction of the quantitative study-specific questionnaire (study III and IV). The combination of interviews with observations in the field, additional perspectives were caught by analysing discrepancies between 'what they said' and 'what they did', enriching the findings. The synergy of the results from all four studies, when combining different methods as well as data sources, is best shown in the study of competence. Competence viewed from patient- and caregiver experiences and observations (study I and II) were here contrasted to caregivers' self-reported competence (study III), which is a strength. However, the concept of competence is complex and involves several other aspects not studied in this thesis, e.g. the content and/or quality of received training have not been studied.

Study I and II has some limitations in relation to *credibility*, a term often used for validity in qualitative research referring to the confidence in how well data and processes of analysis address the intended focus [165] with known difficulties for researchers not to add their own subjective perspectives to the phenomena being studied [166]. At first the authors' preconceptions and experience could have influenced data collection and data analysis in a unintended way. According to Granheim and Lundman [166], data gathered in an environment known to the author could have an impact on the answers the participants give in the interviews and in the subsequent analysis. The authors' previous experience from nursing, teaching, intensive care and the studied patient groups have influenced the choice of the care situations studied which could have an effect on how the data collection was performed. The author had however little preconceptions or experience from the home care setting which improved the balancing act during interviews and observations. An observer always has an influence on the observed situation [134] and the presence of the author might have influenced the HC assistants to give a more positive representation of their part in the care. However, the authenticity of the situations observed is supported by the fact that both positive and less positive care situations were observed. Prior to each observation which

could be defined as an intimate care situation, the author asked for permission to participate from the patient. Permission was approved but one occasion when no observation was conducted because the patient wanted privacy while being showered by the caregivers. The face-to-face interviews were all performed in the patients' homes with the risk of other persons overhearing the conversations, although most times a closed door was used to separate the interviewee from others present in the home. One exception was the interview with the patient with impaired speaking abilities caused by a tracheotomy, where the HC assistant interpreted words that the author could not understand fully, which could have altered or limited the answers.

GTM was selected because of its known suitability for studies on social interactions in their natural and daily context [126, 167], which in this study included interactions between patients and their caregivers. Sampling was not possible without the help of a manager at the local municipality, which might have influenced the selection of the four patients enrolled in the study. However, the disparities in the patients' conditions and attitudes, as well as in the caregivers' attitudes and actions, suggest that any influence was not systematic. The field study was based on a small group of patients, which might be a limitation. But owing to the larger number of caregivers that were included, and that the author visited every setting several times over a long period of time, it produced a great variety of interactional data. Theoretical saturation, i.e. when categories were considered fulfilled with no additional data being found by the researcher [122], determined the end-point for data collection. To enhance credibility [166, 168], i.e. that the findings were believable and acceptable and that there was a good match between the authors' observations and the findings presented, a thorough and accurate description of methodology and results were illustrated with quotations and extracts from the material and by comparing new categories constantly with raw data and new data with established categories, during the analyses. [124]. Issues on subjectivity and credibility have been considered throughout the research process with frequent supervisions and regular discussions with colleagues in academic seminars. Rigor was ensured by thoroughly following the chosen methodology, by transcribing all interviews immediately after the interview and by frequently writing memos throughout the process. As far as transferability [169] is concerned, although grounded in empirical data, the theoretical models that resulted from the field studies (study I and II) should be regarded as a set of proposals. They are substantive theories that are applicable to the context from which they emerged, i.e. patients receiving and caregivers delivering 24-hour home care in a medium-sized Swedish city. However, these theories might also have relevance for similar situations and contexts In this thesis, the substantive theories were later used in the construction of a study-specific questionnaire.

The *validity* of the quantitative questionnaire studies (study III and IV) has some limitations. Due to the lack of central registry of caregivers in HMV care, the number of eligible respondents was an estimate, and the response rate (60%) is therefore a calculation based on those assumptions. However the difficult process of finding and obtaining respondent information, i.e. correct number of caregivers per workplace, the response rate may be considered acceptable. One major limitation of the study was the lack of information on how many respondents completed the questionnaire from each workplace, thus preventing comparisons related to patient characteristics, nor whether there were respondents from all 28

workplaces who accepted participation in the study or not. This was a necessary restriction in order to perform the study because patients and respondents accepting the study had been promised confidentiality, ensuring that no answers should be traceable to any specific patient and his/her care team.

Another limitation is the use of a self-constructed questionnaire, by nature not validated. However, no validated instrument was found to answer the study aims, to investigate a group of caregivers in HMV care regarding their background and perceptions of competence, responsibility and working conditions. A majority of the questions were based on previous results from the qualitative study. Competence, difficult to measure, was here studied as a self-reported perception which contributed to interesting results, regardless the respondents' actual competence. As a complement, more in-depth information on the respondents' formal healthcare training and content of received supervision and on-the-job training would have been desirable. The use of a validated instrument on perceived working condition and the comparison with a population-based sample increased the validity of the study. The analysis of the caregivers' perceptions of competence and perceived responsibility (study III) were performed by the process of grouping respondents' four-point answers into an index followed by dichotomization. Calculated internal consistency and goodness-of-fit (full and reduced regression models) were both found acceptable. The HC assistants' perceived working conditions (study IV) were analysed according to the validated instrument by Karasek et al. [141] and Theorell et al [139]. One weakness was low internal consistency calculated using Cronbach's alpha for some of the indices, lowest for perceived stimulance (0.37) and perceived social support (0.47). Low internal consistency was also calculated for perceived stimulance among medical secretaries by Theorell et al. [138]. Despite the use of a validated instrument on perceived working conditions, there were difficulties when comparing the study group with the comparison group because the Health Survey [136] did not include full indices, restricting analysis to separate questions only. Additionally, some of the questions on the respondents' workplace background were asked broadly and binary, leading to some missed information, i.e. 'on-the-job training on the home ventilator' lacked information on continuous training, 'clinical supervision' lacked information on type, leader competency or frequency, and 'bullying and/or discrimination' lacked important information by whom, what type etc.

The studies in this thesis were performed in a Swedish context regarding laws, regulations and organisation of health care, and may therefore perhaps be limited in terms of generalisability in every aspect to other countries. The data collection was performed in Stockholm County with several municipalities, hospitals and specialised care facilities, and the findings might therefore best apply to similar-sized areas. However, the recruitment from two HMV-clinics resulted in participating workplaces that were well spread within the selected geographical area, which is considered a strength. A potential weakness was not including the experience of patients' family in the studies. Despite the knowledge of their importance, a decision was made to restrict the aim to include patients and their caregivers only.

These studies address 24-hour home care from the perspectives of the patient and caregiver, i.e. an 'inside perspective'. The patient perspective was the focus of the initial qualitative study, using interviews and observations (study I), whereas the caregiver perspective were the

main focus of studies II-IV. These perspectives together may be considered as an ‘inside perspective’. As it was not the purpose of these studies to provide an ‘outside perspective’ by studying direct organisational aspects of home care, information regarding responsibilities within and between organisations or external quality measurements was not within scope.

7 CLINICAL IMPLICATIONS

The findings in this thesis point at some challenging areas for improvements when providing 24-hour home care for patients in need of advanced care and technology. Patients and caregivers were found compensating when the care and/or work situation was not suited to their needs. This knowledge could be used as a basis for reflection during planning of care for individual patients. By studying the role of the caregivers in HMV care in terms of their own perceptions, a deepened understanding of their working situation was obtained, which could be useful as a platform for further discussions on professional growth and development. Competence and responsibility must be considered when organising 24-hour home which includes advanced care and technology to enhance patient safety and caregivers' working condition. This is a responsibility shared between the employers of the caregivers and the HC professionals responsible for patients' care. Supported by the results in this thesis, a set of proposals to enhance safe care and good working conditions are here summarised as proposed implementations.

- To guarantee an acceptable level of competence in this type of care, there are several factors to consider. Firstly, the need of formal health care training should be addressed. Further, specific training programmes need to be implemented and consequently evaluated for quality and efficiency. A certification for caregivers specially trained in HMV care could enhance quality of care and also stimulate the caregivers to grow professionally in their positions. Learning at the workplace by colleagues should be encouraged, however supported and supervised by HC professionals for quality control.
- The caregivers' 24-hour responsibility for their patient need to be further evaluated. Patients' autonomy, practise of delegations and the use of self-care are issues to consider.
- Sufficient support from the management designed to suit patients, individual caregivers and workgroups, must be implemented. Examples are managerial support with defined leadership, clinical supervision adapted to home care, and support from HC professionals competent in advanced care and technology.
- Patients and caregivers need to be connected to the care system, and communication and collaboration between all actors involved, i.e. patient/caregiver, home care, primary care and specialist care, are of outmost importance.
- The caregivers' psychosocial working environment needs special attention to reduce risks of bullying and/or discrimination at the workplace. The responsibility for caregivers' working environment lies with the employer, often a local municipality or a private agency.
- This study indicated that older and formally trained caregivers take more responsibility than others. Measures must therefore be taken to identify and stimulate caregivers to remain in 24-hour home care, and develop their roles as 'including caregivers', thus taking an overall responsibility for the workplaces.

8 CONCLUSIONS

In their strivings to combine safe care with good working conditions, the caregivers for patients in need of 24-hour home care, including advanced care and technology, were found to compensate. The patients strived for control and safety, and were also found compensating when their care was not suited to their needs.

Caregivers in HMV care with limited formal training self-reported their competence as high and their working conditions without any clear signs of job strain. The findings indicate training and support as important job resources which may balance negative effects in HMV care.

Four factors describing how patients and their caregivers could manage in 24-hour home care were identified:

1. Patients' and caregivers' abilities to compensate, i.e. to take own control and use their own strategies when support from managers and HC professionals are lacking.
2. On-the-job training , i.e. a workplace with apppropriate conditions to provide on-the-job training, which was shown to correlate with caregivers' perception of their own competence, responsibility and control, and gave the patient an experience of being in safe hands.
3. 'One-patient care' with designated caregivers providing options for individualised care
4. 'Including caregivers' taking an overall responsibility for the workplace, contributing to safe care and good working conditions.

In spite of the identified factors describing how patients and caregivers managed their 24-hour home care on their own, and the advantages this may have, gaps identified in these studies should be pointed out. The studies confirm a need for training and support, and therefore patients and caregivers should not be left to manage care on their own. One of three caregivers identified bullying and or discrimination in the workplace, signaling a need for increased organisational support. Additional gaps identified in these studies are a well-functioning chain of care and quality control of patient care and work environment.

When hospital care 'moves home', great challenges arise concerning how to organise safe care for the patients and good working conditions for the caregivers. This thesis points out competence and responsibility as important issues to consider when organising home care for patients in need of advanced care and technology.

9 FUTURE PERSPECTIVES

This thesis has raised several issues in need of further research regarding home care to patients in need of advanced care and technology.

More in-depth studies, preferable with a multi method approach, are needed to gain important knowledge on aspects not included in this thesis within the areas of training and support. Is formal healthcare training important? What are the specific training needs for caregivers working in 24-hour home care? What type of training and support, what kind of content, provided by whom and how often? Studies on caregivers working environment and conditions are also needed, with special focus on the psychosocial aspects of working in a patients' home.

The consequences of transfer of responsibility by delegation from healthcare professionals to the caregivers within advanced home care are in need of further study. Further, to enhance quality management in home care, studies relating the occurrence of reported adverse events or incidents and quality of care to competence are needed.

Patients' families were also excluded from study in this thesis, although the family perspective is important in many aspects and certainly in need to be studied as well. Moreover, the consequences for patients over the age of 65 in need of 24-hourhome care including HMV and normally not eligible to receive one-patient care by designated caregivers due to Swedish regulations, need to be further evaluated.

Finally, further studies on how to best organise adequate HMV care, both from a patient safety and a working condition perspective, are needed. With the focus on competence, a construction of standardised training programmes for HMV care followed by studies for purposes of validation, implementation and evaluation could be beneficial and potentially be used as the foundation for future certifications for caregivers in HMV care.

10 SAMMANFATTNING PÅ SVENSKA / SUMMARY IN SWEDISH

BAKGRUND

Vården blir alltmer avancerad och teknisk och trenden är att den i ökande omfattning ’flyttar ut från sjukhusen’ och hem till patienterna. Patienter i behov av avancerad och teknisk vård, t ex behov av hemventilator, kan behöva 24-timmars (24-tim) hemvård av anställda vårdare vilket ställer stora krav på hur vården organiseras, koordineras och drivs. I dag tar kommunalt eller privat anställda vårdare (personliga assistenter, undersköterskor och vårdare), med låg eller obefintlig vårdutbildning samt begränsat stöd från sjukvården, ett stort ansvar för patienter med stora behov i hemmen. Forskning inom hemvård i allmänhet, och inom hemventilatorvård (HMV-vård) i synnerhet, pekar på brister i framförallt vårdarkompetens och stöd från sjukvården, vilket i sin tur riskerar att påverka såväl patientsäkerhet som kvalitet. Dessutom finns evidens för att vårdande yrken är extra utsatta för negativ påverkan genom höga krav och låg kontroll vilket kan påverka vårdarnas upplevda fysiska och psykiska arbetsmiljö. När avancerad och teknisk vård ’flyttar hem’ får det konsekvenser för patienten, vårdarna, vården och samhället, och detta behöver studeras.

MÅLSÄTTNING

Den övergripande målsättningen med denna avhandling var att söka en ökad och fördjupad kunskap om hemvården för patienter i behov av avancerad och teknisk vård. Ytterligare målsättningar var att undersöka hur patienter i 24-tim avancerad och teknisk hemvård och deras vårdare upplever och hanterar sin situation, samt att undersöka vårdarnas upplevda kompetens, ansvar och arbetssituation.

MATERIAL OCH METOD

Avhandlingen består av fyra delstudier: Två kvalitativa (I-II) och två kvantitativa studier (III-IV). Studie I och II genomfördes som en fältstudie i patienters hem med observationer och intervjuer av patienter i 24-tim hemvård och deras vårdare. Datainsamlingen pågick över en period av två år och Grundad teori (eng. Grounded theory) användes som metod. I studie I redovisas resultat från fyra patienter och deras 19 vårdare ur ett patientperspektiv och i studie II redovisas resultat från de 19 vårdarna ur ett vårdarperspektiv.

Studie III och IV genomfördes som en enkätstudie baserad på en annan grupp vårdare (n=128) som arbetade med patienter i behov av 24-tim hemventilatorvård (HMV-vård). En kartläggning genomfördes av vårdarnas sociodemografiska och arbetsplatsmässiga bakgrund. I studie III undersöktes vårdarnas upplevda kompetens och ansvar med deskriptiv statistik och logistisk regressionsanalys. I studie IV undersöktes vårdarnas upplevda arbetssituation med hänsyn till deras upplevelse av psykiska krav, kontroll, stimulans, socialt stöd samt arbetsmiljö och ett validerat instrument i enlighet med Krav-Kontroll-Modellen användes. I studie IV gjordes även en jämförelse mellan de 128 vårdarna och en populationskontrollgrupp med vårdare inom generell hemvård (n=585)

från ett hälsoenkätmaterial avseende upplevd arbetssituation. Deskriptiv statistik, t-test och chi2 användes.

RESULTAT

Studie I och studie II visade att patienterna och vårdarna, när de upplevde brister, använde sig av kompensatoriska processer i sin strävan efter god och säker vård samt en god arbetssituation.

I studie I är resultatet en grundad teori om patienternas utsatthet samt deras kompensatoriska processer illustrerade genom kärnprocessen 'Grasping the lifeline'. Patienterna strävade efter en säker och trygg vård genom att *ta kontroll* då de själva valde vårdare de kände sig trygga med, *söka sig till trygga händer* genom att instruera nya och okunniga vårdare i svåra moment, och genom att *navigera sin egen vård* då de koordinerade sin egen vård, ibland med hjälp av en vårdare.

Studie II är även den ett resultat av en grundad teori där fyra barriärer identifierades som utgjorde svårigheter för vårdarna. Dessa svårigheter kompenserades för genom kärnprocessen 'strävan att kombinera säker hemvård med en god arbetssituation'. Vårdarna kompenserade sin kompetensbrist med *dagligt lärande* (on-the-job-training), sin utmaning att arbeta professionellt i det privata hemmet genom att *balansera i patientrelationen* och bristen på formellt ledarskap genom att *styra själva.* När patientens vårdkedja ej fungerade grep vårdaren in och *navigerade patientens vård*, tillsammans med patienten eller på egen hand. Genom att använda alla kompensatoriska processer kunde vissa vårdare sägas ha ett inkluderande förhållningssätt. Den 'inkluderande vårdaren' kompenserade då både för sina egna men även andras brister, t ex genom att aktivt delta i kollegialt lärande, att ta ett informellt ledarskap eller att balansera patientrelationer för att undvika konflikter och favoriseringar. Den 'inkluderande vårdaren' tog på detta vis ett övergripande ansvar för vården och arbetsplatsen.

I studie III och IV studerades 128 vårdare som arbetade med patienter i behov av 24-tim HMV-vård. Två tredjedelar var kvinnor, 41% var födda utanför Sverige och åldrarna var jämt fördelade. Drygt hälften, 55% (n=70), av vårdarna saknade formell vårdutbildning, 27% (n=34), hade tagit kortare kurser, och 19% (n=24) hade undersköterskeutbildning eller motsvarande. Hälften av vårdarna var anställda av en kommun och hälften av ett privat vårdbolag/assistansbolag. Flertalet (85%) hade fått arbetsplats-utbildning i ventilatorvård (on-the-job training) och ca hälften hade regelbunden handledning på sin arbetsplats.

I studie III undersöktes vårdarnas upplevda kompetens och ansvar. En stor andel (80%) skattade sin kompetens högt, och ca hälften (59%) skattade sitt ansvar som stort. Starka samband fanns mellan *on-the-job training* och upplevd hög kompetens och stort ansvar. Starkt samband fanns även mellan *handledning* och stort ansvar. Män saknade formell vårdutbildning i större grad än kvinnorna och skattade även sin kompetens lägre.

I studie IV undersöktes vårdarnas upplevda arbetssituation i egenskap av psykiska krav, kontroll, stimulans, socialt stöd och arbetsmiljö. De 128 vårdarna upplevde lägre psykiska krav i jämförelse med kontrollgruppen av vårdare i generell hemvård. *Psykiska krav* skattades högre av utlandsfödda och dem som hade fått handledning; den egna *kontrollen* skattades

högre av äldre vårdare och dem som hade fått on-the-job training; *stimulans* skattades högre av kvinnliga vårdare och dem som hade formell vårdutbildning. Inga samband hittades för socialt stöd. Flertalet av vårdarna (76%) planerade att stanna kvar på arbetsplatsen i minst två år, och en tredjedel (29%) rappoterade att det förekom mobbing och/eller diskriminering på arbetsplatsen.

SLUTSATSER

Patienterna och deras vårdare hanterade den avancerade och tekniska hemvården till stor del på egen hand trots de upplevda bristerna i utbildning och stöd från arbetsledning och sjukvård. Med stöd av avhandlingens studier identifierades fyra förklarande faktorer på hur patienter och vårdare, i strävan efter god och säker vård och en bra arbetssituation, hanterade sin 24-tim hemvård:
1. Patientens och/eller vårdarnas *förmåga att kompensera*, dvs. tar egen kontroll och använda egna strategier i brist på stöd från arbetsledning eller sjukvård.
2. Arbetsplats med goda förutssättningar för *on-the-job training*, vilket visade samband med vårdarnas upplevelse av kompetens, ansvar och kontroll samt gav patienterna en upplevelse av att vara i goda händer.
3. Möjligheten till *singel-vård*, dvs. patient med en egen grupp vårdare, där ’lära känna’ och ’lära sig det specifika’ är viktiga trygghetsfaktorer för såväl patienten som för vårdarna.
4. Förekomsten av *inkluderande vårdare* på arbetsplatsen, dvs. vårdare som tar ett övergripande ansvar för vården och arbetsplatsen och därmed bidrar till god och säker vård och en bra arbetssituation för alla.

Trots de identifierade faktorerna på hur patienter och vårdare hanterar sin 24-tim hemvård ’på egen hand’ och med de eventuella fördelar som detta medför, måste även de brister som studierna lyft fram betonas. Studierna bekräftar behovet av *utbildning* och *stöd*, och därför bör patienter och vårdare ej lämnas att hantera vården själva. En av tre vårdare uppgav att mobbing och/eller diskriminering förekommit på arbetsplatsen vilket också signalerar behov av ett ökat organisatoriskt stöd. Ytterligare behov som får stöd i avhandlingen är en välfungerande vårdkedja samt kvalitetsäkring av såväl patientvården som arbetsmiljön.

Att avancerad och teknisk vård ’flyttar hem’ är en utmaning och resultaten i denna avhandling belyser *kompetens* och *ansvar* som viktiga fokusområden att beakta inom avancerad och teknisk hemvård. Studiens resultat kan bidra till en fortsatt utveckling av vårdarrollen inom HMV-vård.

11 ACKNOWLEDGEMENTS

The Centre for Family Medicine (CeFAM) has been the 'home' for my doctoral studies for the past eight years, and it has indeed been an inspiring journey. CeFAM, with collaborations between Karolinska Instituet and Stockholm County Council, is a modern institution which encourages a multi-professional atmosphere. Seminars discussing perspectives from different healthcare professions make a perfect soil for a junior researcher like me to grow. The Heads of CeFAM during this time; former Jan Sundquist and Lars Agréus, and presently Gunnar Nilsson, are highly appreciated for making this creative environment possible.

My special thanks go to:

Ingrid Hylander, my main supervisor and co-author. You have been my support and inspiration throughout my long journey and for that I am forever grateful. I will miss our long sittings and your endless patience trying to explain to me the world of codes, categories and core processes (in grounded theory), but I will also remember our small-talks and laughs. You are my role-model for a great supervisor!

Eva Hammar Chiriac, my co-supervisor and co-author, for inviting me into the world of group processes and field observations. You are the best proof-reader among us!

Hans Michélsen, my co-supervisor and co-author, for sailing into my life just when I needed you: To construct a questionnaire! Your consistency when teaching me the mystery of work condition indices by Karasek I will remember and cherish.

Lena Törnkvist, my co-supervisor and co-author, for grounding my research findings in the profession we both share, that of nursing. Thank you for opening your door to guide me in the complex world of primary care!

Barbro Mendel, my mentor, for being so encouraging and a good listener. With you, I've been in safe hands!

Sven-Erik Johansson and **Robert Szulkin**, for your valuable statistical assistance.

Colleagues and friends at CeFAM; **Mia Barimani Anita Berlin, Sonja Modin** and **Lena Lund** for our valuable discussions on qualitative research, **Daphne Macris** for your expertise in the art of popular writing, **Cecilia Wittzell-Tibbling** for keeping an eye on my money, **Georg "Jojje" Holm** for being my *live* IT-support, **Yvonne Jaurell** for making me feel at home, **Angela Gompaki** for helping me in the jungle of KI-rules, and **Lena Olsson** for your helpfulness (and shared love for horses).

Annemarie Kennestad, for your expertise and guidance in my search and understanding of laws and regulations on home care.

Lice-lotte Grandin, Södertälje kommun, for being my 'gate-keeper' prior data collection for the field study.

Klara Geisewall, NRC (Nationellt Respirationscenter), Danderyds sjukhus and **Anna Vide,** Andningsmottagningen, Neurologkliniken, Karolinska Huddinge, for helping me to come in contact with caregivers for the questionnaire study.

The patients who participated in my study and to those who inspired me to seek more knowledge in HMV care. A special thanks go to **Staffan Ericsson,** the bravest patient I know!

All caregivers in HMV care in Stockholm County who participated in the questionnaire study.

Hans Selldén, for sharing your extensive knowledge concerning HMV care with me; both from the perspective of a physician and that of a patient with HMV.

Oscar Rüdeberg, for helping me understand the unique work of a caregiver in HMV care.

Kajsa Giesecke, REMEO Stockholm, for opening my eyes for research and for all your support, from start to finish. Your energy and entrepreneurship is a unique combination, and as my former and present manager, you have always encouraged me to bring myself to a higher level. With you by my side everything has been possible!

Louise Claesson, my closest colleague and dear friend, for your support and patience with me at times when my thesis studies interfered with our work. We complement each other and the results are stunning!

Mia Barimani, my closest doctoral co-student, for our growing friendship while struggling with our separate studies. You a midwife and me an ICU-nurse make a perfect balance!

Michael Gårdebäck, Södertälje sjukhus, my former manager, for your support and your endless enthusiasm for clinical research, big and small.

All my present colleagues at REMEO Stockholm, for your patience with me when finishing my thesis. And remember: We make a difference to our patients!

All my previous colleagues at the intensive care unit, Södertälje sjukhus, for giving me 12 years of collegial and social companionship I will always cherish.

The network for clinical teachers in intensive care in Stockholm, for our collaborative and intellectual discussions on intensive care and teaching. We make ‘on-the-job training’ for real!

And finally, to my husband **Michael** for being my highly qualified assistant during all these years of me studying. You have helped me through the practical parts of the research process, for which I am very, very grateful. Thank you, love you. And to **Daniel** and **Johanna**, our lovely children, for making a greater meaning and balance in our lives.

Funding

This thesis and studies were supported by the Regional Agreement on Medical Training and Clinical Research (ALF) between Stockholm County Council and Karolinska Institutet, Södertälje sjukhus, and REMEO Stockholm, AGA Gas AB, Linde Healthcare.

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